

**PERSPECTIVES OF THE INFLUENCE OF STIGMA ON CARE-  
SEEKING BEHAVIOUR AMONG ETHNIC RUSSIANS LIVING WITH  
HIV/AIDS IN IDA-VIRUMAA, ESTONIA.**

by

Tyler Wood

B.A., University of Northern British Columbia, 2008

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## **Abstract**

Since 2001, Estonia has been struggling to contain its explosive HIV epidemic, yet despite years of interventions, adherence to antiretroviral therapy remains between 20% and 40%. The purpose of this research was to examine how HIV stigma is influencing care-seeking behaviour of people living with HIV (PLWHIV) in Ida-Virumaa County, Estonia. This study identified that HIV stigma presents a serious challenge for PLWHIV. The findings not only identified clear cultural metaphors and stigma of HIV and PLWHIV, but also identified that fear of disclosure of status and discrimination from healthcare providers represent significant barriers to care for PLWHIV. The findings also identified that the combination of HIV stigma, fear of disclosure, discrimination from healthcare providers and certain state policies have fostered an environment of structural discrimination that not only limits PLWHIV in Ida-Virumaa ability to access care, but also pushes them away from the healthcare system.

## Table of Contents

Abstract .....	i
Table of Contents .....	ii
List of Tables .....	v
List of Figures .....	vi
Acknowledgements .....	vii
Chapter One: Introduction .....	1
General Context .....	3
Defining the Problem and Purpose of the Study .....	12
Contextualizing: Necessity and Importance of this Study .....	13
Partners .....	18
Location of the Study: Ida-Virumaa .....	19
Narva .....	21
Kohtla-Järve and Jõhvi. ....	23
Chapter Two: Literature Review .....	27
Symbolic Interactionism and Origins of Stigma Theory .....	27
Stigma and Social Control Theory .....	29
Disease Stigma and the Process of Disease Stigmatization .....	36
Chapter Three: Methods and Methodology .....	40
Ethnography .....	40
Setting: Ida-Virumaa .....	44
Research Design .....	45

Sampling .....	47
Research Procedure and Ethical Considerations.....	51
Entering the Field.....	53
Data Collection. ....	55
Data Analysis .....	59
Chapter Four: Results .....	65
Olga's Story .....	65
Introduction to Analysis.....	72
HIV Stigma .....	73
HIV Stigma: Perspectives on HIV.....	75
HIV Stigma: Perspectives of People Living with HIV.....	85
Barriers to Care: Fear of Disclosure .....	99
Barriers to Care: Discrimination by Healthcare Providers .....	104
Being talked down to. ....	105
Refusing to Provide Adequate Care.....	107
Unprofessional Behaviour and Acts of Discrimination.....	109
Lack of Knowledge.....	113
Lack of Faith in Healthcare Providers. ....	116
Summary.....	127
Chapter Five: Discussion .....	129
Cultural Metaphors of HIV and Disease Stigma .....	129
Barriers to Care.....	136

Fear of Disclosure .....	137
A Poisoned Relationship: PLWHIV and Healthcare Providers.....	142
Stigma and Structural Discrimination.....	146
Limitation.....	156
Chapter 6: Conclusion.....	160
Recommendations.....	163
References Cited .....	166
Appendix I .....	186
Appendix II .....	189
Appendix III.....	191
Appendix IV.....	196
Appendix V.....	200
Appendix VI.....	202

## List of Tables

Table I .....	50
Table II .....	74
Table III .....	75
Table IV .....	106

## List of Figures

Figure 1 .....	4
Figure 2 .....	5
Figure 3 .....	20
Figure 4 .....	21

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## **Chapter One: Introduction**

Since the fall of the Soviet Union in 1991, post-Soviet countries in Eastern Europe and Central Asia have been struggling to contain and control a rapidly growing human immunodeficiency virus (HIV) epidemic. While from 1995 to 2010 many geopolitical regions, including Sub-Saharan Africa, were able to lower the spread of HIV and the number of HIV related deaths, the HIV prevalence rate in Eastern Europe and Central Asia increased by more than 250% from 2001 to 2010 (UNAIDS, 2011, p. 8). Although there are some differences between countries, Eastern Europe and Central Asia's HIV epidemic is predominantly driven by the use of intravenous drugs, and the epidemic is primarily concentrated in intravenous drug-using populations. The concentration of HIV within the intravenous drug-using population is a result of the complicated economic, political, and social chaos that occurred as post-Soviet states transitioned from the Soviet system, along with the explosive rise of crime and the international drug trade throughout Eastern Europe and Central Asia (Feshbach, 2006; Paoli, 2002a, 2002b; Wallander, 2006; Zigon, 2011).

In response to the epidemic, the countries of Eastern Europe and Central Asia have incorporated different public policies and programs to control both the increase in HIV and intravenous drug use as well as to provide services for both those living with HIV and the resulting acquired immunodeficiency syndrome (AIDS) and for intravenous drug users (IDUs)<sup>1</sup>. Even though some countries and programs have been more successful than

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<sup>1</sup> In this thesis, I have utilized abbreviations to refer to populations of individuals who share similar behaviours or status, such as intravenous drug users (IDUs), and people who live with HIV/AIDS (PLWHIV). I have used these abbreviations solely for the purpose of aiding the reader, and not as a means of generalizing or dehumanizing the members of these populations. Through the course of this thesis, I ask the readers to understand that the individual members of these populations are vulnerable people who face

others, public perspectives, nationalism, ethnic divisions, government policies and stigma of HIV, AIDS and of at risk populations, particularly IDUs, represent a significant barrier to the efficacy of these programs (Feshbach, 2006; Gilinskiy, 2006; Hønneland & Rowe, 2005; King, Maman, Bowling, Moracco, & Dudina, 2013; Lowndes, Alary, & Platt, 2003; Nivikov, 1987; Orlova, 2009; Paoli, 2002a, 2002b; Platt, Wall, et al., 2006; Rhodes et al., 2002; Rhodes et al., 2006; Rhodes et al., 2012; Rowe & Rechel, 2006; Sarang, Rhodes, Sheon, & Page, 2010; Shilovskaya; UNGASS, 2010; Wallander, 2006; Zigon, 2011). For example, the Russian Federation, the most influential state within the region, has implemented strict laws that punitively target drug users, which have resulted in the outlawing of methadone replacement therapy, the use of safe injection sites by police as a means to bait and arrest IDUs (Rhodes et al., 2006; Sarang et al., 2010), and the current political discussion to create forced labor camps, commonly known as *gulags*, for Russia's estimated 8 million IDUs (Tétrault-Farber, 2015).

Unlike the Russian Federation, Estonia has adopted a very different approach to address its HIV epidemic, which includes the implementation of a variety of public health programs including safe injection sites, methadone replacement therapy, and antiretroviral therapy<sup>2</sup> (ART) available at no cost to anybody living with HIV and or AIDS<sup>3</sup>. Through its policies and its approach, Estonia's response to the HIV epidemic has been relatively successful and reduced the country's HIV incidence rate from 107.8 per 100,000 in 2000 to 40.8 per 100,000 in 2008 (Estonian Health Board, 2010). However,

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significant challenges and barriers in their day-to-day lives. Furthermore, it is important to remember that the members of these populations are unique individuals, each with his or her own personal story.

<sup>2</sup> Although it is referred to as ART in this thesis, Estonia provides Highly Active Antiretroviral Therapy (HAART) to all people living with HIV. The ART acronym was used in place of HAART for two reasons. First, while in the field, healthcare providers and PLWHIV only referred to HAART as ART (APB/ART). Second, to make the text more reader friendly.

<sup>3</sup> The free access to ART for anybody living with HIV is a new policy change that was implemented in 2015. Prior to 2015, ART was available at no cost only to PLWHIV who have a CD4 count of <350/mm<sup>3</sup>.

there are still some substantial obstacles hindering Estonia's ability to make further progress in containing the epidemic. One of these obstacles is that only 16% of Estonia's estimated 11,000 PLWHIV/AIDS are accessing ART, and there is a gap in the literature about access and adherence to ART in Estonia. Another obstacle is that HIV is predominantly concentrated within Estonia's ethnic Russian (or Russian-speaking) minority. This is particularly problematic as there are strong political, economic, ethnic divisions between the Estonian majority and the marginalized ethnic Russian minority. Furthermore, the Russian Federation's government could portray strong negative metaphors of HIV, IDUs, and public health interventions to Estonia's ethnic Russians, as it continuously exerts its political and nationalist ideology throughout Eastern Europe through its monopoly of Russian-language traditional and online media.

This qualitative, exploratory ethnographic study documented the perspectives and experiences of HIV stigma by people living with HIV/AIDS (PLWHIV) and people not living with HIV/AIDS in Ida-Virumaa County, Estonia and examined the influence HIV stigma has on care-seeking behaviour. Using a conceptual framework based on social-control theory, this study investigated how internalized stigma and external stigma impact the daily life of PLWHIV in Ida-Virumaa and identified strategies used by individuals to navigate the stigma to access care and ART. As this study was ethnographic in design, data collection took place in the three communities of Ida-Virumaa, the city of Narva, the town of Kohtla-Järve and the town of Jõhvi.

## **General Context**

Estonia is a post-soviet Eastern European country and EU member located on the Baltic Sea of Northern Europe (see Figure 1 and Figure 2). With a population of

1,340,000 and geographical territory of 45,227 square kilometers, Estonia has never been a dominant player on the global stage; however because of the country's geographical location, Estonia has been coveted by the major Northern European powers from the thirteenth century through the end of the Cold War in 1991 (T.U. Raun, 2001, p. xviii).

Figure 1

Map of Estonia In Europe



(Wikimedia Commons)

Because of the country's desirability by other major European powers, Estonians did not hold sovereignty over their native homeland for much of the past millennia as the present day country was occupied and controlled by different geopolitical powers including the Swedish, Danish, Polish, German and Russian empires. Estonia and the other Baltic States, Latvia and Lithuania, were able to gain their independence in 1920 as a result of the chaos that rose from the Russian Empire's 1905 revolution, World War I, and the Russian communist revolutions of 1917 (Bouchard, 2003, p. 86). This freedom was short-lived as the Soviet Union annexed the Baltic States after the Molotov-

Ribbentrop Pact in 1940 (T.U. Raun, 2001, p. 139). The Baltic States had once again found themselves to be the pawns of the great powers of Europe. Over forty years later, the volatile political environment that beset the political elite of the Soviet Union during the mid 1980s created a framework for the Baltic States to affirm their autonomy. When the Soviet Union collapsed in 1991, the Baltic States quickly declared their independence.

Figure 2

Map of Estonia



(U.S Passports & International Travel)

The social and economic chaos that followed the fall of the Soviet Union resulted in a dramatic increase in infectious diseases in the post-soviet countries of Eastern Europe, including an explosive HIV epidemic (Laisaar, Avi, DeHovitz & Uusküla, 2011; Rüütel & Uusküla, (2006); Twigg, 2006; UNAIDS/WHO, 2013; UNGASS, 2010). Unlike the Russian Federation and Ukraine, whose HIV epidemics rapidly developed in

the early and mid 1990s, the HIV epidemic in Estonia did not start until 2001 (UNGASS, 2010, p. 0). Although the first case of HIV in Estonia was registered in 1988, there was a very low HIV incidence rate during the 1990's with a total of only 96 HIV cases registered in the country from 1988 to 1999 (UNGASS, 2010, p. 0). However, in the year 2000, 393 new HIV cases were identified, an incident rate of 28.5 cases per 100,000, and 92% of these cases were concentrated in Estonia's Ida-Virumaa county (Laisaar, Avi, DeHovitz, & Uusküla, 2011, p. 843; UNGASS, 2010, p. 0). In 2001, the number of new HIV cases increased exponentially to 1473, an incidence rate of 108.3 per 100,000 (Estonian Health Board 2010; UNGASS, 2010, p.0). Similar to the year 2000, the majority of the cases identified in 2001 were concentrated in the city of Narva, the largest city in Ida-Virumaa, and Tallinn, the capital of Estonia (Laisaar et al., 2011, p. 844).

Since 2001, Estonia's HIV incidence rate has steadily decreased from 66.3 per 100,000 cases in 2002 to 46.7 in 2008 (Estonian Health Board 2010). Despite the decrease in the number of new annual cases, Estonia's 2008 incidence rate was one of the highest incidence rates in the European Union (EU) (Uusküla et al., 2008, p. 119). Moreover, in 2009 Estonia had the second highest HIV prevalence rate in Europe rate at 1.3%, which was just behind Ukraine at 1.6%, but larger than the Russian Federation's estimated 1.1% (Laisaar et al., 2011, p. 843).

What further complicates Estonia's HIV epidemic is that despite the country's efforts to control it, the use of active antiretroviral therapy (ART) by PLWHIV is limited. Even though the Estonian government provides ART to PLWHIV at no cost, of Estonia's estimated 11,000 PLWHIV, only 1793 were receiving ART at the end of 2010, and it is estimated that there are 3,000 cases in need of ART (Laisaar, Uusküla, Sharma,

DeHovitz, & Amico, 2013, p. 2; Uusküla et al., 2012, p. 1471). Significant steps have been made since 2010 to increase adherence, but the estimated adherence rates in Ida-Virumaa is still between 20% and 50%.<sup>4</sup> Monitoring ART adherence has also been problematic in Estonia due to both limitations of patient surveillance and misconceptions of ART held by PLWHIV (Laisaar et al., 2013; Uusküla et al., 2012). Imperfect adherence to ART presents a particular challenge to Estonia's healthcare providers because it can not only prevent viral suppression in individual cases but can also lead to the evolution of drug resistant HIV strains and death (Bangsberg, 2006, p. 939).

Unlike other regions with large HIV epidemics that are driven by heterosexual encounters, Eastern Europe's and Central Asia's HIV epidemic is driven by intravenous drug use. Prior to the fall of the Soviet Union in 1991, illegal drug trafficking was limited within the Soviet Union as closed borders and tight regulations on the mobility of citizens and goods restrained the supply and demand for illegal drugs and constricted the Soviet Union's involvement with international drug trafficking (Orlova, 2009, p. 23). However, the combination of political, economic and social difficulties of the 1990s and the opening of the borders to international trade and markets enabled the explosion of domestic and international illegal drug markets in the former countries of the Soviet Union (Orlova, 2009, p. 23; Paoli, 2002b, p. 168).

During the 1990s, illegal drug use exploded in Russia and other post-Soviet countries. In Russia from 1988 to 2000, the number of drug-related crimes per 100,000 increased from 8.6 to 167.33 (Gilinskiy, 2006, p. 274). The rise in drug use in the region

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<sup>4</sup> These figures of ART adherence are based on the estimations of healthcare providers working with ART and HIV researchers at the University of Tartu and Estonia's National Institute for Health Development who I met and spoke with while in the field. Updated publications of the estimations of ART adherence for Tallinn and Kohtla-Järve are presently in the process of being published, but I was asked by the authors not to quote or source the exact figures until the article is published.

was contributed to the combination of both poor individuals who sought an escape from the desperate socio-economic chaos of the 1990s and by individuals who wished to practice popular western social-cultural trends (Orlova, 2009, p. 24). During the mid 1990s, intravenous drug use with heroin and other opioids increased in popularity and decreased in prices as the restructuring of the drug trade enabled easier movement of heroin and other opioids from Afghanistan, Chechnya and Pakistan to Eastern and Western European countries (Gilinskiy, 2006, p. 277; Orlova, 2009, p. 24; Paoli, 2002a, p. 22).

Like the other post-Soviet countries, Estonia's HIV/AIDS epidemic has traditionally been driven by and primarily concentrated in the intravenous drug-using population, and the number of cases related to intravenous drug use still greatly exceeds the number of cases of heterosexual transmission among the general population (Rüütel, Trummal, Salekešin, & Pervilhac, 2011, p. viii). There is also no evidence indicating high incidence rates among men who have sex with men (MSM), but there are growing concerns about high HIV prevalence and incidence among commercial sex workers, particularly those who are intravenous drug users (Rüütel et al., 2011, p. viii). In 2015, however, the nature of HIV's epidemic began to change as two thirds of new HIV cases were identified as members of the general population (BNS, 2016). Despite this significant change in the spread of the epidemic, HIV is still primarily concentrated in the intravenous drug using community, and depending on the geographic region, the prevalence rate among IDUs ranges from 50% to 90% (Platt, Bobrova, et al., 2006, p. 2120; Uusküla et al., 2008, p. 121). In comparison, the HIV prevalence rate for IDU's in Canada is approximately 16.9% (Canada, 2012, p. 2)



Another critical aspect of Estonia's HIV epidemic is that HIV infections are predominantly concentrated in the country's ethnic Russian minority. Although the ethnic Russian minority equates to approximately 25% of Estonian's population, 85% of all Estonia's IDUs are ethnic Russian men (Priimagi & Ruutel, 2006, p. 142). Moreover, the Ida-Virumaa region, which is almost explicitly populated by ethnic Russians, has the country's highest incidence rate of 110/100,000, and the HIV prevalence rate among IDUs in Ida-Virumaa exceeds 90% (Platt, Bobrova, et al., 2006, p. 2120; Priimagi & Ruutel, 2006, p. 142; UNGASS, 2010, p. 1). Excluding Tallinn, Estonia's capital and largest city, which also has a large population of ethnic Russians and the country's second highest HIV incidence rate of 38/100,000, Ida-Virumaa's incidence rate is more than 11 times higher than the HIV incidence rates of all of Estonia's other regions combined (UNGASS, 2010, p. 1).

The concentration of HIV in Estonia's ethnic Russian minority is the result of Estonia's economic, political and social transition in the 1990s and of ethnic tensions and divisions between the Estonian majority and Ethnic Russian minority that date back to the USSR's annexation of Estonia in 1940. After it regained its independence from the Soviet Union in 1991, Estonia underwent radical changes in international relations and economic policy that resulted in the transition of Estonia's economy and political relations away from dependence on Russia and other pro-Russian, post-Soviet countries to developing economic and political relations with the European Union (EU) and Finland, which eventually led to Estonia becoming a member of the EU and NATO (Lauristin & Vihalemm, 2009, p. 2). This significant political-economic transition also resulted in the collapse of Ida-Virumaa's industrial sector and infrastructure, which had

been explicitly tied to Soviet industry along Estonia's Eastern boarder (Tammaru & Marksoo, 2011, p. 224). Consequently, Ida-Virumaa has had the country's highest unemployment rate since the early 1990s even during the times of economic booms Ida-Virumaa's unemployment was rate 4 to 5 times higher than Estonia's other regions (Tammaru & Marksoo, 2011, p. 24).

In addition to the economic reforms, Estonia's social transition also resulted in a rise in ethnic tensions between the ethnic Estonian majority and the ethnic Russian minority. Viewing the ethnic Russians who immigrated to Estonia during the Soviet Union as foreign "occupiers" who annexed Estonia in the 1940 Molotov-Ribbentrop Pact between the Germany and the Soviet Union, the Estonian government initiated an era of ethnic-nationalist social, political and economic policies that were designed to safeguard the Estonian culture and language, which is only spoken in Estonia, from influence and assimilation by Russian and or English culture (Raun, 2009, p. 528; Thompson, 1998, p. 111).<sup>5</sup> These policies, which include: strict language criteria for citizenship, education policies, and social and economic preferences to speakers of Estonian, have resulted in both a non-violent ethnic conflict from the failure to integrate the Estonian majority and the ethnic Russian minority, and the continued social, economic and political marginalization of the ethnic Russian minority (Feldman, 2005, p. 678; Galbreath, 2008, p. 93; Toivo U. Raun, 2001, p. 35).

Despite these cultural cleavages and the fact that ethnic Russians born in Estonia, except a minority who either had grandparents or great grandparents living in Estonia

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<sup>5</sup> While Estonian's viewed ethnic Russians and members of other ethnic groups who migrated to Estonia from different regions of the Soviet Union as foreign invaders or occupiers, ethnic Russians saw themselves very differently. Some saw themselves as liberators who freed the Estonia's from Nazi rule, while others saw themselves as fellow Soviet citizens moving to one of the more liberal areas of the country.

prior to the Soviet annexation or the few whose family were members of Estonian Independence movements prior to 1991, are not granted Estonian citizenship until they pass an Estonian language exam, the Estonian government has always actively included the ethnic Russian population in its efforts to control the HIV epidemic. However, because of the cultural divide between Estonians and ethnic Russians and the Russian Federation's overwhelming domination of the Russian language media in Estonia, especially television, the Estonian government's efforts to address the epidemic and provide ART is at risk of being undermined by the very strong metaphors and perspectives of HIV, IDUs, and other at risk groups, as well as ideology and nationalism promoted by the Kremlin, Russian state-sponsored media, the Russian Orthodox Church and independent nationalist groups (Raun, 2009, p. 531).

Given the current political and economic instability in the EU and Eastern Europe, the power of HIV and IDU stigma promoted by the Russian Federation could represent a significant obstacle for Estonian's public health efforts in Ida-Virumaa. Russia has a long history of dismissing its own massive HIV epidemic, creating propaganda-rich metaphors about the disease and restricting access to services needed by people living with HIV/AIDS (PLWHIV) and other high-risk populations, restricting services offered by non-government organizations (NGOs) and demonizing those most at risk of HIV infection (Lowndes et al., 2003, p. 47; Rhodes et al., 2006, p. 920; Wallander, 2006, p. 43). If the stigma, propaganda and ideology of HIV and IDUs catered by Russian policies, right-wing nationalist groups and other agencies have taken root in the perspective of HIV held by Estonia's ethnic Russian population, then PLWHIV in Ida-Virumaa and IDUs health-seeking behaviour could be severely inhibited

by the fear of stigmatization, which could be a factor in the low number of ART adherence. Be that as it may, identifying, addressing and understanding how PLWHIV in Ida-Virumaa identify and experience stigma and perceive ART could provide a significant insight into the care-seeking behaviour of HIV-positive Russian speakers which could increase participation and adherence to ART.

### **Defining the Problem and Purpose of the Study**

The purpose of this study was to document the contemporary perceptions, cultural metaphors and stigma of HIV held by PLWHIV in Ida-Virumaa and sought to understand how these stigmas and metaphors influence PLWHIV's care-seeking behaviour. My central research question was how does HIV stigma influence the care-seeking behaviour and access to care for PLWHIV in Ida-Virumaa? This ethnographic study also contains five additional sub-questions that were investigated:

- 1) What are the shared cultural metaphors and understandings of HIV and AIDS in Ida-Virumaa?
- 2) How do individual PLWHIV experience HIV stigma, and how do they view the influence of stigma in their daily lives?
- 3) Does HIV stigma represent a barrier to accessing care, and if so, how does the experience or fear of stigmatization prevent individuals from accessing care?
- 4) How do individual PLWHIV navigate stigma in order to access care?
- 5) How do HIV stigma, fear of stigmatization and conceptions of ART create a barrier to accessing and/or adhering to ART?

The applied aim of this study was to contribute to the literature about access to ART in Estonia by providing a thorough examination of the influence of HIV stigma on the daily lives of PLWHIV in Estonia, and document how HIV stigma represents a

barrier to accessing ART. The findings of this study provide valuable insight into how HIV stigma acts as a significant barrier to accessing care, and that the combination of HIV stigma, location of services, government policy and the behaviour of some healthcare providers represent a significant barrier to the efficacy of ART adherence programs and other HIV focused public health interventions.

### **Contextualizing: Necessity and Importance of this Study**

The overall purpose of this study is to understand how HIV stigma influences perspectives of the disease, how care-seeking behaviour effects enrollment and adherence to ART among PLWHIV in Ida-Virumaa, and to contribute to the literature of HIV in post-Soviet countries. The escalating HIV epidemic in Eastern Europe and Central Asia presents a serious challenge for the governments, economies and people living in the region. Between 1995 and 2010, there were significant and/or steady decreases in the HIV incidence and/or prevalence rates and number of deaths in regions with large HIV epidemics including South Africa, South Asia, South-East Asia, Latin America, and the Caribbean (UNAIDS, 2011, pp. 7-9). However, the HIV prevalence rate in Eastern Europe and Central Asia increased by more than 250% between 2001 and 2010 (UNAIDS, 2011, p. 8). What is even more problematic about the epidemic is that 90% of the region's HIV cases are concentrated in two countries that are currently facing severe economic, political, and social instability: the Russian Federation and Ukraine (UNAIDS, 2011, p. 8).

Since the emergence of HIV in the Soviet Union in the early 1980s, the disease has continuously been associated with powerful and misleading metaphors of the disease, and power stigmatization of those with the disease and those perceived to be at risk of

contracting the disease. During the era of the Soviet Union, HIV was primarily perceived by the Soviet Government as an “African” and “Western” disease, and that the people of the Soviet Union’s superior cultural morals and practices and believed absence of promiscuous behavior, homosexuality, commercial sex workers, and drug use would protect them from contracting HIV (Feshbach, 2006, p. 7). Moreover, HIV was often perceived as a foreign invader manufactured by the United States (Feshbach, 2006).

In addition to the misconceptions of the cultural metaphors of HIV, the Soviet Union and the current Russian government have consistently portrayed HIV as a moral punishment for socially deviant behaviour. During the time of the Soviet Union, the state’s portrayal of HIV effectively entrenched powerful negative perspectives and stigmas about HIV and PLWHIV/AIDS in public discourse (Feshbach, 2006, p. 34). The effects of the Soviets Union’s portrayal of HIV are clearly demonstrated in a letter that was written by 16 graduates of a medical institute in 1987 to the head of the Soviet Union’s Federal AIDS centre:

Dear colleagues: We graduates of a medical institute are categorically opposed to combating the new “disease” AIDS! And we intend to do everything in our power to impede the research for ways to combat that noble epidemic. We are convinced that within a short time AIDS will destroy all drug addicts and prostitutes. We are confident that Hippocrates would have approved of our decision. Long live AIDS! (Nivikov, 1987)

The perspective expressed by these medical graduates is troubling and also influences the current HIV epidemic in Estonia. Many of the healthcare providers, particularly doctors, in Ida-Virumaa were trained during the Soviet-era, and some healthcare providers still hold perspectives similar to those expressed in the letter.<sup>6</sup>

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<sup>6</sup> The results and discussion chapters provide detailed descriptions of these perspectives, and how they continue to influence the care-seeking behaviour by PLWHIV in Ida-Virumaa.

In his 1987 formal briefing on AIDS to the United Nations General Assembly, Jonathan Mann warned the world that HIV stigma represents a serious challenge to national and global efforts to address HIV, as policies of discrimination or exclusion and improper public education campaigns will force those living with HIV to go “underground,” which ultimately undermines a state’s effort to address the epidemic (Mann, 1988, p. 134). The literature has also clearly defined the influence stigma has on health-seeking behaviour and ART adherence (Alonzo & Reynolds, 1995; Chesney, 2003; Cunningham et al., 1999; Deacon, 2005; Earnshaw & Chaudoir, 2009; Parker & Aggleton, 2003; J. Sayles et al., 2008; J. N. Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). Yet, the metaphor of disease as a punishment and the perspectives of HIV promoted by the Soviet Union continue to influence HIV stigma in post-Soviet countries, including Estonia, but particularly in the Russian Federation (Feshbach, 2006; Goodwin et al., 2003; Hønneland & Rowe, 2005; Jerker & Rifat, 2008; Rhodes et al., 2006; Sarang et al., 2010; Wallander, 2006; Zigon, 2011).

Since Vladimir Putin came to power in 2000, the Russian government has been reluctant to address the country’s growing HIV epidemic, and has maintained an ideology that HIV is a problem of developing countries and not of global powers like the Russian Federation (Wallander, 2006, p. 42). Consequently, Russia’s HIV and IDU policy has been riveted with inaction, public downplay of the severity of the epidemic, minimal allocation of funding, and policies that punitively target IDUs, which included outlawing methadone replacement therapy, while at the same time enabling and supporting organized crime and drug dealers. (Feshbach, 2006; Gilinskiy, 2006; King et al., 2013;

Orlova, 2009; Paoli, 2002a; Rhodes et al., 2006; Sarang et al., 2010; Wallander, 2006; Zigon, 2011).

Unlike the Russian Federation, the Estonian Government has been very proactive in its efforts to combat HIV, and has always included the ethnic Russian minority in its efforts. However, despite the adoption of harm reduction programs, methadone replacement therapy, the funding of NGOs and the implementation of no-cost ART program for PLWHIV, Estonia is still struggling to control its HIV epidemic. This inability to control the epidemic has also gained unfortunate international attention. In February 2016, the embassies of the United States of America, the United Kingdom and Finland addressed the Estonian parliament, the *Riigikogu*, informing them that the Estonian government has not done enough to significantly address the HIV incidence rates and that epidemic at-risk of becoming out of control (Poverina, 2016). This is of particular concern because the USA, UK and Finland have been providing financial support for Estonian HIV programs for years.

Studies on the relationship between stigma and care-seeking behaviour, particularly in Ida-Virumaa, have been extremely limited. The findings of this study will contribute to the very limited literature regarding access and adherence to ART and perspectives of HIV in Estonia and Eastern Europe. Like other Eastern European countries, HIV research in Estonia has primarily focused on IDUs while some focus has been placed on commercial sex workers and other high-risk populations. Very little research has examined other important aspects of the epidemic including access to care, adherence to therapy and socio-cultural factors like stigma or social-support for



PLWHIV, which has created a large gap in the English published literature about access and barriers to ART in Estonia (Laisaar et al., 2013, p. 1; Uusküla et al., 2012, p. 1470).

Exploring the relationship between perceptions of ART and HIV stigma held by PLWHIV in Ida-Virumaa, shines a metaphorical light on how stigma or stigmatization influences health-seeking behaviour among PLWHIV in Ida-Virumaa as well as identify the internalized and external stigma experienced by PLWHIV. Despite the substantial progress Estonia has made in addressing the country's HIV epidemic, very few PLWHIV/AIDS are accessing ART. In 2010, only 16.3% (1,793) of people living with HIV in Estonia received ART and approximately 27.3% (3000) of the population was in need of ART (UNODC/WHO, 2011, p. 33; Uusküla et al., 2012, p. 1471). These numbers are perplexing because ART is offered free of charge to those with or without health insurance. However, the low adherence to ART also implies that there are barriers preventing people from accessing ART.

Research of local beliefs of HIV held by the people of Ida-Virumaa has been very limited. This study successfully identified HIV stigma as a barrier to care-seeking behaviour and ART adherence, as well as identified the cultural metaphors of HIV and PLWHIV present in Ida-Virumaa and how these metaphors perpetuate HIV stigma and the discrimination of PLWHIV in Ida-Virumaa. Moreover, this study also identified two ways that HIV stigma influence whether or not a PLWHIV will access care: a fear of being identified as having HIV, and repeated experiences of discrimination and unprofessional behaviour from healthcare providers. This exploratory study's goal was to provide valuable data for Estonia's public health researchers and planners and aid them in

their efforts to address the epidemic, and thereby expand the effectiveness of ART and other public health services in Ida-Virumaa.

## **Partners**

To facilitate this research, this study was undertaken in collaboration with the Estonian Network of People who Live with HIV/AIDS (EHPV). The EHPV is Estonia's only NGO that specifically provides services for, supports and advocates on the behalf of PLWHIV in Estonia. Although a board and regional staff oversee many of the projects and initiatives undertaken by the organization, the EHPV has many members and volunteers who are both PLWHIV and people not living with HIV. In addition of running public awareness campaigns regarding HIV and overseeing HIV testing, provides a lot of essential services for PLWHIV including's access to psychologists, social workers and peer-councilors. The EHPV plays a very important role as liaison between PLWHIV and government services. The organization and its membership was the driving force behind the opening of the Linda Clinic in Narva, which was only successful due to the EHPV's campaign petitioning the Estonian government to increase HIV-related services in Narva.

For this study, the EHPV staff and volunteers enabled the success of the study. They not only enabled me to gain access to the different cities, but also enabled participant recruitment and spent a lot of time and effort teaching me about the many difficulties facing PLWHIV in Ida-Virumaa and Estonia. In return for their invaluable service, upon completion of the study, I will be providing the EHPV multiple reports about the study's findings.

## Location of the Study: Ida-Virumaa

This exploratory ethnographic study included an 8-week field study in Ida-Virumaa County, Estonia. Ida-Virumaa is the most North-Easter territory of Estonia, sharing a border with Russia to the east, and the Baltic Sea to the North (see Figure 3 and Figure 4). Ida-Virumaa is predominantly populated by Estonia's ethnic Russian minority, and is often considered to be an Estonian, Russian motherland, or *russskaya rodina*.<sup>7</sup> As an individual travels the highway between Tallinn and Narva the buildings begin to slowly transition from the Estonian and European style of architecture to the very large, Soviet style apartment buildings. This transition is particularly visible between Jõhvi and Narva. While Jõhvi has a few four to five story apartment buildings, most of the residential buildings are only two to three stories, with many single-family houses developments surrounding the town. As you drive closer and closer to Narva, the single family houses and small apartments buildings slowly become replaced by the larger five to eleven story Soviet-era apartment buildings.

Ida-Virumaa was a very important place for this study. During the time of the Soviet Union, it was a region of great prosperity, but since the 1990s Ida-Virumaa has been struggling with Estonia's highest unemployment rates and little social mobility for people living there (Tammaru & Marksoo, 2011). The post-Soviet transitional period was very difficult for the people of Ida-Virumaa, as many of the mines, and industries, which

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<sup>7</sup> The Russian term *rodina* roughly translates as motherland or homeland, but has many different interpretations. By calling Ida-Virumaa as *rodina*, some may inference this as meaning that the territory should belong to Russia, which is an argument often used by the government of the Russian Federation. However, this is not how the people of Ida-Virumaa use the term. Bouchard (2003) identified, the difference to between the "big *rodina*", the Russian nation, and the "small *rodina*", the geographical region were a person grew up. The meaning, therefore, of Ida-Virumaa being a Russian *rodina* is that it is a place where many ethnic Russians were born and live, and not that it is a part of the rightful territory of the Russian Federation.

were directly tied to the Soviet/Russian economy, were suddenly isolated from the Russian economy. This leads to vast unemployment, an increase in criminal activity, a rapid rise in intravenous drug use, and the HIV epidemic. HIV incidence and prevalence has consistently been highest in Ida-Virumaa County, and although national incidence rates have decreased for much of Estonia, incidence rates remain high in Ida-Virumaa. This study examined HIV within three different communities in Ida-Virumaa: Narva, Kohtla-Järve and Jõhvi.

Figure 3

Map of Estonia's Counties



(WineandVineSearch)

HIV incidence and prevalence has consistently been highest in Ida-Virumaa County, and although national incidence rates have decreased for much of Estonia, incidence rates remain high in Ida-Virumaa. This study examined HIV within three different communities in Ida-Virumaa: Narva, Kohtla-Järve and Jõhvi.

Figure 4

Map of Ida-Virumaa



(www.globalsecurity.org)

HIV incidence and prevalence has consistently been highest in Ida-Virumaa County, and although national incidence rates have decreased for much of Estonia, incidence rates remain high in Ida-Virumaa. This study examined HIV within three different communities in Ida-Virumaa: Narva, Kohtla-Järve and Jõhvi.

### **Narva.**

Located on the Estonian-Russian boarder, Narva is the largest city of Ida-Virumaa County and is Estonia's third largest city with a population 62,100 (NDDE, 2013, p. 8). Like the county as a whole, Narva is primarily populated by ethnic Russians who make-up 82.21% of the population (NDDE, 2013, p. 9). Beside ethnic Russians, the larger ethnic groups in the city include Estonians (3.75%), Ukrainians (2.46%), Byelorussians (2.05%), Finns (0.71%), and Tatars (0.48%) (NDDE, 2013, p. 9). Narva is separated from

Russia by the Narva River, which serves as a geographical border, and the Russian city of Ivangorod located on the opposite (Eastern) bank of the Narva River. Because of the city's close proximity to the Russia Federation, the large number of ethnic Russians and the current geopolitical tensions, there is a lot of concern held by Estonians, and other members of NATO and the EU that Russia may try to annex Narva (Berman, 2014; Morris, 2014; Whitmore, 2015).

During the time of the Soviet Union, Narva was a jewel of Soviet manufacturing and industry. The city is filled with large factories and office buildings that used to house some of the largest manufacturing factories of the Soviet Union's industrial empire. However, the fall of the Soviet Union resulted in serious economical and social consequences for the city of Narva. Many of the great factory buildings are still present, but nearly all of them have been abandoned, and stand as ruins of the Soviet legacy. The city is also home to some newer Western style malls and shopping centers, and many of the old Soviet apartment buildings, that were not abandoned, have been restored with murals painted on their sides. Despite the consecutive economic hardship the city has faced, the people of Narva are proud of their home, and this pride can be seen in the clean streets, the colourful remodeling of buildings, and the relatively and carefully looked after playgrounds that stand in almost every apartment building's yard.

Narva provides an interesting location for the proposed study for four reasons. First, Estonia's HIV epidemic initially started in Narva when, in 2000, there was a significant increase in the number of HIV cases among the city's IDU population (Priimagi & Ruutel, 2006, p. 141). Second, due to Narva's close proximity to the Russian Federation, it was important to examine the HIV and IDU stigma held by the ethnic

Russians and to see if it is different from the cultural metaphors promoted by the Russian government. Although the literature has clearly defined that Estonia's ethnic Russians do not want to join Russia (Berman, 2014; Bouchard, 2003; Černov & Kisseljova, 1995; Ehala, 2009), the perspectives of HIV and IDUs held by Narva's ethnic Russians could be very similar to those of Russia, or there might be a symbolic competition between the different metaphors of HIV, IDUs and ART. Third, there are very few publications about HIV in Narva, as the city has been poorly represented in the scientific literature. Finally, despite being the third largest city in Estonia and the largest in Ida-Virumaa, Narva has the least amount HIV-related services available for PLWHIV. Despite having between 2000 and 2500 registered HIV cases<sup>8</sup>, Narva has only one full time *infectionist*<sup>9</sup> specialist who is legally allowed to subscribe and monitor ART to PLWHIV. In addition to the full time *infectionist*, who works at the Narva Hospital, Linda Clinic, ran by the AIDS Healthcare Foundation (AHF), also has one par-time *infectionist*, who provides services to PLWHIV every Thursday.

### **Kohtla-Järve and Jõhvi.**

During the Soviet era, Kohtla-Järve and Jõhvi used to be a part of the same town/region, and presently the communities share many of the same services, including hospital, methadone replacement centers, polyclinic, and HIV centre. In the early 1990s, however, the towns were separated from each other, and have become very different.

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<sup>8</sup> These estimated numbers were obtained from speaking with different healthcare providers who work with HIV in Narva. Despite great effort to obtain an exact number of registered PLWHIV cases in Narva, neither my gatekeepers nor I were able to gain access to these figures from the Narva Hospital.

<sup>9</sup> The word *infectionist* is a Russian term for a doctor who is an infectious disease specialist. In Estonia, PLWHIV can only receive HIV related services, treatment, and medication from an *infectionist* or an *infectionist's* office. The *infectionist* being responsible for all HIV related services and treatment often causes difficulties for PLWHIV who are seeking non-HIV related medical care from general practitioners or other healthcare providers. This will be discussed in more detail later in the results chapter.

Kohtla-Järve is not so much a city or a town, but rather a collection of small mining and industry towns separated by 6 to 30 kilometers of highway. Prior to world war two, the region of present-day Kohtla-Järve and Jõhvi was a bog. However, when rich shale oil deposits and other petroleum products were discovered, it was geographically converted into a livable place for humans, industry and agriculture. During the Soviet Union, many shale-oil mines were established and around the mines small towns were built to provide residents and services for the miners and other workers. Prior to the fall of the Soviet Union, there was a plan to develop all the mining and industry towns of Kohtla-Järve into one city, but this plan was canceled when Estonia gained its independence.

The town/region of Kohtla-Järve (population 37,000) is a collection of six different mining towns that include: Kohtla-Järve or Järve (the main administrative district) with a population of 17,000, Ahtme, which is also referred to by its Soviet name Puru, with a population of 17,200, Kukurse with a population of 500, Oru, with a population of 1,200, Sompa with a population of a 1,000, and Vivikonna with has a population of 100. Although geographically close to each other, many of these towns are separated by long stretchers of highway, which makes traveling between some of the towns a very difficult task. For example, if an individual needs to travel from Sompa to the Kohtla-Järve hospital located in Ahtme, he or she would need to take an hour-long bus ride to get to the hospital.

Although the majority of its population is ethnic Russian, Kohtla-Järve is a very different city and has a different atmosphere than Narva. There is an abundance of abandoned and condemned residential and factory buildings, that identify that not so long



ago the region once supported a much larger population. The sense of civil pride that was easily visible in Narva cannot be seen in Kohtla-Järve. Where in Narva I rarely saw graffiti, graffiti is present on many of the buildings in Kohtla-Järve. Many of the people live in near poverty, with few jobs that offer wages higher than minimum wage, which is barely enough for the people to survive on<sup>10</sup>. Moreover, employment opportunities remain limited, especially to those who do not speak Estonian. The continuously poor economic situation of the city has also caused many people to turn to crime and Kohtla-Järve and substance abuse, and the city has a very large number of intravenous drug users.

While living in Kohtla-Järve, I spent most of my time in Järve and Ahtme. I was interested in traveling to the other towns, particularly Sompa, which has a very high number of PLWHIV and IDUs and almost no employment opportunities, but the staff of the EHPV repeatedly told me not to travel to the other towns out of fear for my personal safety. Even while traveling throughout the city, Elena Antonova<sup>11</sup>, my main gatekeeper, showed me buildings and individuals to avoid because of their association with local organized crime.

Although once part of the same region, the town of Jõhvi seems to be in almost a completely different world than Kohtla-Järve. The buildings are well maintained, the streets are regularly cleaned, and the town seems to be an economic-hub of the region. Although it has a relatively small population of only 11,000, Jõhvi has three shopping

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<sup>10</sup> Estonia's current minimum wage is €390 (\$576.90 CND) per month.

<sup>11</sup> Mrs. Elena Antonova, did provide me written and verbal consent to share things she told me and to use her real name in this publication. One of the reasons for this is that her active role as an HIV advocate in Ida-Virumaa makes her easily identifiable to people living in Ida-Virumaa and Estonia. The other reason for using her real name in place of a pseudonym, is that she is currently one of only two staff members of the EHPV who actively works in Ida-Virumaa, and anybody who reads this document and accesses the EHPV website would be able to identify her as my gatekeeper.

malls, at least three large building supply stores, many fancy motels and expensive restaurants and a large number of small businesses. Although Jõhvi is only 1/6<sup>th</sup> the size of Narva, it is the administrative capital of Ida-Virumaa, but even being the capital makes it hard to understand the visible differences in socio-economic status between Kohtla-Järve and Jõhvi. One interesting note, is that in comparison to Narva and Kohtla-Järve, about a third of Jõhvi's population is ethnic Estonian.

Kohtla-Järve and Jõhvi share many of the same health resources including hospitals, infectious disease clinic and ART centre and methadone replacement therapy centers. People in Kohtla-Järve who wish to access methadone need to travel to Jõhvi, while PLWHIV living in Jõhvi need to travel to the town of Ahtme in Kohtla-Järve to access ART. Unlike Narva, Kohtla-Järve and Jõhvi are well represented in the scientific literature of HIV in Estonia, and unlike Narva has three infectious disease specialists. Because of their close proximity to each other and that the communities share HIV related services, they were considered to be the same geographical region for the purposes of this study.

## **Chapter Two: Literature Review**

### **Symbolic Interactionism and Origins of Stigma Theory**

Symbolic interactionism is a theoretical approach that sees social and symbolic meanings as an interactive process. As a theory of knowledge, symbolic interactionism perceives meaning as an interaction between three themes: symbols, process, and interaction. In symbolic interactionism, humans use symbols to assemble and express meaning including self identification and expression of emotions and thoughts, understanding of the world around us and perspectives of the wider social order (Plummer, 1991, p. ix). The second theme, process, emphasizes that, like societies and language, meaning, symbols and understanding of the self are always evolving, transforming and changing through the interaction and encounters with other individuals and the world (Plummer, 1991, p. ix). The final factor of symbolic interactionism, interaction, sees that understanding of symbols and one's self is an interaction relationship between an individual and other individuals within a society and the society as a whole (Plummer, 1991, p. x).

Discussions and analyses of HIV stigmas are predominantly based on the social interactionism theories of Erving Goffman. Goffman described stigma as a visible or invisible "attribute that is deeply discrediting" that is viewed as not coinciding with the cultural construction of what that individual should be (Goffman, 1963, p. 5). More specifically, he defines stigma as a "special kind of relationship between an attribute and a stereotype (Goffman, 1963, p. 4)." If an attribute is viewed to be against either a cultural norm or idea of how an individual should be or behave, then a metaphor can be created that will symbolically separate or remove the individual from the norm. These

metaphors and images are then spread through daily discourse creating a shared cultural perspective towards individuals with a particular stigma, which effectively reduces the opportunity and life-chances of the individual (Goffman, 1963, p. 5).

Goffman saw that the sociological relationship between what he described as a *normal*, a member of the population who follows societal expectations and norms, and a person with a stigma was also influenced by societal politics. Depending on the severity of the metaphor attached to the stigma, a stigmatized individual is required to manage his or her stigma in two environments: within the group of people with the particular stigma, and with other groups of people including the society as a whole (Goffman, 1963, p. 123). While caught between these distinct groups, the society informs the stigmatized person that despite the reasons for the stigma, this person is still a member of the wider group. However, Goffman describes this as a *phantom acceptance*, for despite being told they are members of the larger group, the structure and ideology of a society directly or indirectly reminds the individuals that they should not abandon their stigmatized group, and that they are not truly accepted members of the society (Goffman, 1963, p. 124). Moreover, Goffman saw that professionals can limit the ability of a stigmatized individual's ability to function in society by, "Tell[ing] him what he should do and feel and what he is and isn't and all this purportedly in his own interests" (Goffman, 1963, p. 124).

The level of a stigmatized individual's acceptance into society depends solely on the power of the metaphors attached to the stigma and the understanding society has of the stigmatized condition, which will inform a non-stigmatized member of the general population of how to view and treat individuals with the stigma (Goffman, 1963, p. 122).

However, if the stigma is believed to be a result of a person's choice and not an accident, it may be perceived as result of *social deviance*. Goffman describes *social deviance* as a practice when a group of individuals who either do not or refuse to follow the stereotype, or culturally created role, ascribed to them come together to form their own communities or groups (Goffman, 1963, p. 143). In other words, *social deviance* is the practice of behaviours and/or beliefs that are not perceived as being acceptable by society such as drug use, commercial sex work, homelessness, body art, and/or membership in a subculture. Despite the constellation of historical, political, cultural, economic and structural factors that may lead a person to join, groups that are *socially deviant* are viewed as a threat to society because, "they are perceived as failing to use available opportunity for advancement in the various approved runways of society; they who open disrespect for their better; they lack piety; they represent failures in the motivational schemes of society (Goffman, 1963, p. 144). Socially deviant groups are often looked at by fear and distrust because they are able to recruit *normals* into their group (Goffman, 1963, p. 145).

### **Stigma and Social Control Theory.**

Although Goffman did examine the importance of politics and history on the creations of metaphors of stigma, the majority of research into stigma has examined how individuals are perceived and the consequences or acts of discrimination that result from these perspectives when one individual discriminates against another (Deacon, 2005, p. ix; Link & Phelan, 2001, p. 366; Parker & Aggleton, 2003, p. 15). However, as the social and cultural understandings of stigma are shared, reinforced and practiced by a group and

not simply a result of individual behaviour, stigma is closely associated with power and the structure of society (Parker & Aggleton, 2003, p. 17).

Social Control Theory provides an effective means of exploring the relationship between stigma, stigmatization and the influence of power within society. In sociology, Social Control Theory argues that members of societies use “social controls” to regulate and conform themselves to desired principles, values, and perspectives of their society (Janowitz, 1975). Social Control Theory has been used to study delinquency and argues that delinquency, or deviancy, is intrinsic to human behaviour, and that individual’s willingness to conform or not conform to society was dependent on the relationship between an individual and other individuals as well as with his or her society (Wiatrowski, Griswold, & Roberts, 1981). As it argues that social controls regulate individual behaviour while simultaneously identifying deviant behaviour, Social Control Theory also argues that social controls operate to the advantage of the dominant members, or groups, of society by perpetuating social inequalities within the society (Deacon, 2005, p. 84; Link & Phelan, 2001, p. 375).

The role of power in the creation, reinforcement, and discrimination of stigma is overlooked because people’s attention is so focused on the stigmatizing attribute or condition that the power difference between the people who have the condition and those who do not is as Link and Phelan describe, “so taken for granted as to seem unproblematic” (Link & Phelan, 2001, p. 375). In the case of HIV in Russia, *normals* see HIV high-risk populations, IDUs, female sex workers and people with a criminal past with such strong negative perspectives that they never focus on the structural power

apparatus of the Russian society and miss how and why people become members of these *socially deviant* groups.

For social control theorists, stigma, including disease stigma, is not only a shared ideology about an undesirable trait, behaviour, or condition, but also a symbol. Stigma can be viewed as a symbol when it arises from a value-based ideology that imposes moral judgments on others to ensure the safety and authority of the non-deviant's moral identity (Herek, 2002, p. 600). An example of this is the belief in Russia, and in many other places around the world, that HIV is a moral punishment for immoral (deviant) behaviours like intravenous drug use, commercial sex work, or homosexuality.

As it is a symbol, stigma and stigmatization are highly influenced by a constellation of social factors including history or interpretations of history, politics, socio-economic status, and cultural beliefs and ideology (Goffman, 1963, p. 5; Link & Phelan, 2001, p. 367; Parker & Aggleton, 2003, p. 14). Due to its symbolic power, stigma is used by individuals, the elite and the state to both produce and reproduce social inequality and shape the social narrative of a country, and thus can, in itself, act as a means of social control (Parker & Aggleton, 2003, p. 17). The practice of stigma and stigmatization creates significant differences or markings between different categories of people within a society, and these markings dictate the degree individuals are able to interact with the power structure of a society (Parker & Aggleton, 2003, p. 18).

If the dominant members or groups of a society decide to discriminate a stigmatized 'them', they can do so either by convincing the stigmatized persons to accept the stigma mantle, or direct discrimination by creating an ideology, metaphor, and a narrative around the stigmatized people and/or their condition (Link & Phelan, 2001).

This can be done by either convincing those with the stigma that they are deserving of the affliction or behaviour that is stigmatized, or by limiting their accessibility to services offered to the non-deviant members of society. Link and Phelan (2001) describe this situation as structural discrimination where there is an accumulation of institution practice that work to the disadvantage of stigmatized groups by creating a disabling environment that limits the ability of the stigmatized to function in society, such as limiting their ability to afford effective health care or to create a metaphor of fear or shame around them so that others will not want to interact with them (p. 372). Prior to the 2014 Winter Olympics in Sochi, the Russian government passed a vague anti-gay/homosexual propaganda law designed to punish those who would preach nontraditional sexual practices and or homosexual rights to minors. Consequently these laws have led to the pseudo-legalization of extreme violence towards homosexuals, and Russian nationalism has become an accepted platform for antigay groups to post their violent assaults on and torture of members of the Russian homosexual community (Luhn, 2013; Rainsford, 2014).

In addition to facilitating society's fear and mistrust of the stigmatized, structural discrimination also influences how much state resources will be devoted to research and interventions to help the stigmatized, and whether the stigmatized population will be able to receive help and function openly in the society or if they will be forced into the margins or shadows of the society (Link & Phelan, 2001, p. 372).

Understanding the relationship between political and ideological power, public policy and the creation of a stigma and stigmatization are important if the perception or metaphor of the stigma is to change. To date, the majority of interventions designed to



combat stigma within a society focus on educating and changing the behaviour of the discriminators who are seen as extreme individuals who do not represent the ideologies of the society (Deacon, 2005, p. 17; Parker & Aggleton, 2003, p. 14). However, both Link and Phelan (2001) and Parker and Aggleton (2003) argue that, despite interventions to confront or change the symbolism attached to a stigma, the stigma will continue because it is a means of maintaining social control as it creates a sense of control, protection and immunity to the stigmatizing attribute for a group (Deacon, 2005, pp. 16, 18).

Deacon et al. (2005) identify some critical limitations of the conceptualization of stigma as a method of social control. First, placing emphasis on the structure of society, political economy and dominant classes' actions to create and use stigma to maintain a social order, leads to the idea that stigma is functionalist in nature, and that all stigma results in discrimination. The creation and practice of a stigmatizing belief may not result in a *normal* or the state directly (i.e. implementing policies that promote stigma) or indirectly (not addressing discrimination of the stigmatized) discriminating a stigmatized group, but it could result in self-stigmatization, or serve as a springboard for activism and social change (Deacon, 2005, p. 17). By emphasizing macro factors and actions of the state, portrayals of the stigma as a method of social control overlook the importance of agency by those with the stigma and those without.

The second limitation is that stigma is not always controlled, manipulated or utilized by the dominant groups to promote social inequality. Deacon et al. (2005) argues that, even though it is important to understand the relationship between power and stigma, stigmatizing beliefs do not always follow the traditional inequality fault-lines

within a society, nor do they always perpetuate social inequalities (p. 17). Some stigmatizing beliefs may not necessary result in discrimination, but could also result in other negative effects like self-stigmatization, and that discrimination could result from factors unrelated to the stigmatized characteristic (Deacon, 2005, p.17). Although a specific stigma may reinforce existing social inequalities, the stigma itself may not be a direct cause of social inequality or result in acts of discrimination against a stigmatized individual (Deacon, 2005, p.17). For example, although HIV is commonly associated with deviant and high-risk behaviours, an individual living with HIV may not be discriminated against or experience socially or economically marginalized solely because he or she has HIV. In other words, that this individual has HIV does not mean that their families and friends will always turn away from them, nor does it mean that they are either from or will be forced into socio-economic marginalization.

Deacon et al.'s main concern with social control theory's approach on stigma is that it over emphasizes the influence of those in power of the elite in shaping and controlling stigma, while ignoring the affects on individuals living with and without the stigmatized characteristic. They argue that although the effects of specific stigmas may be beneficial to the elite, the elite may not always be directly responsible for shaping the narrative around specific stigmas (Deacon, 2005, p.17). Essentially, the view the social-control theory as a model that emphasizes socially functionality chain of stigma leads to discrimination, and discrimination leads to social inequality (Deacon, 2005, p.17). As an alternative approach to the social-control theory, they propose the blaming model of stigma that emphasizes that, "Stigma is an emotional response to danger that helps people feel safer by projecting controllable risk, and therefore blame onto out-groups.

Stigmatization thus helps to create a sense of control and immunity from danger at an individual and group level” (Deacon, 2005, p.17).

Although Deacon et al.’s blaming model of stigma and criticism of stigma as a means of social-control, the model does face some difficulties when the stigma is stacked with other stigmas and perpetuated by elite groups within a society. In the case HIV in Ida-Virumaa, people living with HIV represent a stigmatized population, within a stigmatized population, in a politically-economically marginalized region of a state, and that these marginalization and stigmatization have been reinforced through both state policy and perspectives of those with power. Although Deacon’s et al. emphasis on the role of the individual and the blaming model of stigma, social control theory is still an relevant theoretical perspective to understand HIV stigma in Ida-Virumaa. This thesis will explore how healthcare providers and government policies perpetuate HIV stigma, discriminate PLWHIV and reduce the access to care that has fostered an environment of structural discrimination for PLWHIV trying to access care in Ida-Virumaa.

Another limitation to the conceptualization of stigma as a means of social control and of Deacon et al.’s blaming model is that neither perspective provides clear examples of how stigma is developed, carried out or practiced. They do not examine how stigma is processed through discourse or how it is used to reflect ideas of ethnic or state nationalism. The main reason for this is that stigmatization is created and fostered by a constellation of different regional and culturally specific factors, and even in the case of Estonia’s Ethnic Russian population, which shares a border with Russia, Russian HIV stigma in Estonia could be very different than HIV stigma in Russia. Parker and Angleton (2003) identified this as one of the most difficult aspects of creating a worldwide

intervention against HIV stigma, as the regionally and culturally specific narratives of a stigma are incredibly diverse (p.15).

### **Disease Stigma and the Process of Disease Stigmatization.**

One of the most common criticisms of stigma research and stigma theory is the vagueness of definitions of stigma in relation to discrimination (Deacon, 2005, p. 15; Parker & Aggleton, 2003, p. 15). Link and Phelan (2001) argue that sigma is defined by the actions of discrimination that result from the stigma symbol. Parker and Aggleton (2003) argue that stigma and the resulting discrimination are a result of political economy, of social exclusion within a society (19). Both of these perspectives lead to the definition that stigma is a social process that reinforces the inequality that already exists in a society. However, when examining diseases, epidemics and disease stigma, it is important to realize that stigmatized beliefs does not always follow the preexisting inequalities within a society, and that stigmatization always result in the creation of social inequality (Deacon, 2005, p. 17).

For the purpose of my research, I will use the definition of stigma proposed by Alonzo and Reynolds (1995). Alonzo and Reynolds revisited Goffman's original definition of stigma and identified that, in addition to being an attribute, stigma is a language of relationships where one individual is labeled as a deviant while at the same time reinforcing the narrative of being normal by those who do the labeling (Alonzo & Reynolds, 1995, p. 304; Deacon, 2005, p. 15). They specifically define the stigmatized as "A category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the

humanizing benefit of free and unfettered social intercourse” (Alonzo & Reynolds, 1995, p. 304).

Stigma ascribed to diseases and illnesses are different from other forms as stigmas because the exposure to the environmental or biological factors that cause the disease may or may not fall along the inequality fault-lines of a society. The presence of disease or an epidemic in a society is very problematic because it interferes or limits an individual’s ability to participate in society. Moreover, illness is a social construct of how people perceive and understand the etiology of a biological or social disease (Alonzo & Reynolds, 1995, p. 305). Although adequate medical and biological knowledge of a disease may help limit the effects of stigmatization, powerful metaphors of the disease are created that often mark those afflicted as sinful, immoral, deviant, evil, and/or deserving of their affliction (Alonzo & Reynolds, 1995, p. 305). Conrad further suggests that metaphors of disease, or disease stigma, either produce or are a product of deviant behaviour (Conrad, 1986, p. 55). The symbolic power of the disease attaches the stigma to social deviance, which may very well ensure that development of structural discrimination for those either afflicted or associated with the disease, which could result in the state’s failure to control or manage an epidemic.

Based on the works of Alonzo and Reynolds (1995), Deacon (2005) defines disease stigma as “an ideology that claims that people with a specific disease are different from ‘normal’ society more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively defined behaviours or groups in society. Disease stigma is thus negative social ‘baggage’ associated with a disease” (Deacon, 2005, p. 19).

She argues that the stigmatization of a disease is a social process where people use shared social representation to distance themselves and their in-group from the risk of contracting a disease by constructing the disease as preventable or controllable; identifying the contraction of the disease as a result of ‘immoral’ behaviors; attaching these behaviours with ‘carriers’ of the disease in other groups; and creating the metaphor that people are deserving of their condition as it is a result of their immoral behaviour (Deacon, 2005, p. 23).

Expanding upon the Alonzo and Reynolds (1995) definition of stigma, and Deacon’s definition of disease stigma, the examination of disease stigma, and of stigma, requires a further analysis of the relationship and symbolism of a stigma that are held by both those with the stigma and those who stigmatize those with the stigma. Deacon (2005) describes how the presence of stigma does not result in discrimination of the stigmatized (Deacon, 2005, p.23). The analysis of a stigma or a disease stigma must first examine separately the internalized stigma, how the disease stigma is experienced and seen by those with stigma, and the external stigma, or how the stigma or condition is perceived by those without the condition, to be able to truly understand the effects of the stigma in a society (Earnshaw & Chaudoir, 2009, p. 1161).

The combination of Alonzo and Reynolds definition of disease stigma and stigma as a means of social control provides an effective framework to explore the cultural meaning of HIV in Ida-Virumaa and identify how HIV stigma influences PLWHIV care-seeking behaviour. This theoretical framework provides an effective means to explore these questions because it is taking into consideration not only how individual’s perceive HIV stigma, but also how government policy, healthcare providers, past ideologies and

cultural perspectives have influenced the meaning of HIV in Ida-Virumaa. However, to effectively explore the research question with this conceptual framework, a methodology needed to be adopted that would enable data collection not only through research participants, but also through daily conversations with the people of Ida-Virumaa.

## **Chapter Three: Methods and Methodology**

### **Ethnography**

Ethnography is a qualitative research methodology utilized by researchers to study and interpret the shared and learned patterns of values, behaviours, beliefs and language of a particular culture-sharing group (Creswell, 2013, p. 90). As a research process, ethnography involves an extended period of observation of the study group, mostly through participant observation, which requires the researcher to immerse himself or herself into the day-to-day lives of the study group, observe their behaviour and practices, and interview group participants (Creswell, 2013, p. 90). The main objective of ethnographic studies is to develop a description of the emic (the perspectives held by members of the particular study group), perspectives, ideas, and beliefs of a group with the end goal of either an analysis of the themes that emerge from the group and an overall interpretation of the themes, or the creation of a holistic cultural portrait of the group that incorporates the views of the participants and the views of the researcher (Creswell, 2013, p. 96).

Originating in the field of socio-cultural anthropology, ethnography provides an unique insight for researchers as through the active observation and participation in the day-to-day activities of a group with a shared culture for a prolonged duration enables the researcher to gain an understanding of how individual members of that group see, understand and experience their world. These aspects enable the researcher to investigate perspectives, beliefs and ideas held by members of the group that may not be obtainable through other study designs. Because of the contact and the duration the researcher has with the group, he or she will be able to develop strong rapport and trust with members of



the group who may become more open to sharing their experiences as well as their private, secret and/or sacred ideas, beliefs and practices with the researcher.

Ethnography is primarily utilized as a means of a qualitative inquiry, and it incorporates varieties of methods for data collection. The method primarily associated with ethnography is participant observation (Van Den Hoonaard, 2012, p. 52). As a method, participant observation is a strategic method of data collection which requires the researcher to become involved in the culture-sharing group in the following ways: learning new languages or dialects, and experiencing the lives of the people being studied as much as possible (Bernard, 2011, p. 258). This prolonged contact between the researcher and the culture-sharing group enables the research to accurately identify the emic perspective, which is how the group views and understands of a particular phenomenon. This is important because the research usually holds an etic perspective, which is the outsider's perspective, of that same phenomenon that could differ greatly from the emic perspective of the study group. Although participant observation can also be used to gather quantitative data, qualitative data is collected through methods such as, but not limited to field notes of the researcher's observations and experiences, audio and/or video recording of narratives, stories or folk tales, and open-ended interviews (Bernard, 2011, p. 257). In addition to participant observation, ethnographic studies can also incorporate a variety of other quantitative methods, such as questionnaires and structured interviews, and qualitative methods, such as semi-structured interviews, to explore and collect data related to the research question.

Even though ethnography does provide many methodological advantages, it also has some critical limitations. First of all, researchers usually use ethnography to study

social-groups or cultures that they do not belong to and may or may not have had significant contact with. If a researcher is interested in studying ideologies and perspectives of a group in a different culture or country, he or she may be required to learn a new language in addition to studying a group who, for a variety of reasons, may view him or her with mistrust, confusion or contempt. Likewise, if a researcher wishes to study a different culture group within their own societies, such as the homeless, a biker gang or a corporation, the group may view the researcher negatively as he or she is not a member of that social group. To navigate these potentially serious barriers to research, ethnographers recruit gatekeepers to aid them in building initial rapport with the group, learning aspects of the culture and language, and helping the ethnographer transition into the daily life and practices of the group. Gatekeeper is a jargon term for individuals who are, hopefully, trusted and respected by the group, and are willing to help the researcher to gain access and develop a working rapport with the group or community. Gatekeepers may or may not be part members of the group the researcher wants to study; however, they are key informants who can not only help the researcher gain access to the group, but also aid the researcher with his or her interpretation and understanding of observations.

A second important limitation of ethnography is that the mere presence of the research may have negative impacts on individuals being studied (Creswell, 2013, p. 96). While in the field, a researcher may come across personal information or behaviour from an individual participant that the participant may be willing to share, but if other community members were to learn about that participant's status, he or she might face negative consequences from the group. This is particularly true if the individual is

engaged in illegal or socially deviant behaviour, as is often the case when the group of interest is associated with criminal activity. Moreover, it is always possible that if police, prosecutors or other legal, social, or cultural authorities learn of the researcher and or about the research project, they may try to confiscate the research data or force the researcher to expose his or her participants.

To successfully limit the negative impacts the study may have on members of a group, researchers using ethnography need to be aware of a possible negative impact their presence and research may have on the individuals and community they are studying. Moreover, it is of critical importance that the researcher is sensitive to the needs of the individuals being studied (Creswell, 2013, p. 96). If the researcher is engaged in examining either a vulnerable group or a group that may be involved in criminal or deviant behaviour, the researcher must develop his or her study to include clear means to ethically protect the anonymity of individual participants at all stages of the research process. Establishing ethical conditions addressing the sensitive needs of the individuals, will not only address the needs of individuals participating in the research and ensure the success of the research, but may also aid in developing trust and rapport with the participants when they see that their needs or concerns were already addressed.

Because it is often required that the researcher spends a prolonged duration of time within a community, ethnographic research does present some risks to the researcher. The personal risks that an ethnographer can encounter in the field range greatly from physical and health risks to psychological and emotional risks to political or geo-political risk. Even with great preparation prior to entering the field, the researcher will never know what may happen in the field, who they may anger, the political

consequences could arise from his or her presence, or if an unexpected conflict will begin during data collection. To avoid these potential risk factors, ethnographic researchers need to develop a set of contingency plans to navigate the potential risk they may encounter in the field, such as multiple plans to evacuate the field on short notice, to gaining access to emergency care, arranging to speak with psychologists or counselors. Gatekeepers are also an excellent in reducing the potential risk a research may encounter in the field. Their knowledge about local affairs, individuals, unsafe locations, and safe locations, is invaluable as learning about potential areas of risk is essential to avoid possible risk.

### **Setting: Ida-Virumaa**

This study was conducted in 3 communities of the Ida-Virumaa County of Estonia: the city of Narva (population 58,375) town of Kohtla-Järve (population 35, 928) and the regional capital, Jõhvi (population 10,775). Ida-Virumaa County is Estonia's northeastern territory with Russia on the Eastern Boarder, and the Baltic Sea on the northern border. Data collection took place within the three communities over an eight-week period from February 7<sup>th</sup> 2016 to March 31<sup>st</sup> 2016. Three weeks were spent in Narva, three weeks in Kohtla-Järve and the remaining twelve days were spent in Jõhvi.

The interviews took place in one of two EHPV regional offices: one located in Jõhvi the second located in Narva. These offices were often vacant and free to use as the EHPV's team in Ida-Virumaa is very small and staff members are required to travel throughout the different communities of Ida-Virumaa. In addition to EHPV staff duties, the offices are also used to host local Narcotics Anonymous meetings, and often used by peer-councilors and traveling psychologists to provide services for local PLWHIV and

IDUs. Because of the relationship with the EHPV, the offices represent a safe and secure location for PLWHIV in the communities.

## **Research Design**

This exploratory, ethnographic study utilized a symbolic interactionism approach to effectively document HIV stigma and examine the relationship between HIV stigma and health-seeking behaviour, in included an eight weeks field study in Ida-Virumaa. Data was collected through the use of semi-structured interviews with PLWHIV, unstructured interviews with healthcare providers, and participant observation. To aid in data collection, Russian-speaking research assistants were hired to aid with conducting the interviews and interviews transcription.

The primary method of data collection was 90 minutes to 2-hour semi-structured interviews. The inclusion criteria for these interviews were that perspective participants were: either HIV positive or members of an at-risk population<sup>12</sup>, were 18 years old or older, and were not cognitively impaired so they can provide informed consent. Participants will not be required to prove their HIV status, but they will need to provide a form of photo identification to ensure they are 18 years old or older. The interview guide for the semi-structured interviews is presented in Appendix I.

In addition to the semi-structure interviews, three, 90 minute to 120 minute unstructured interviews were conducted to examine the perspectives of HIV stigma held by those who are not HIV positive. Inclusion criteria were that perspective participants had to be 18 years old or older, were HIV negative, and were not cognitively impaired, so

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<sup>12</sup> In Estonia, HIV at-risk populations represented by three groups: intravenous drug users (IDUs), commercial sex workers (CSWs) and men who have sex with men (MSM).

they could provide informed consent. The interview guide for the unstructured interviews is presented in Appendix II.

Participant observation was used to supplement the data collected from the interviews. While in the field, daily observations, conversations, experiences and interpretations as well as local media and spoken discourse was collected and recorded in the form of field notes that were analyzed both in the field and after completion of the study. While in the field, I was regularly allowed to shadow and assist different staff members of the EHPV while they traveled and worked throughout Ida-Virumaa. This included participating in public HIV testing and information events sponsored by the EHPV on International Condom Day and International Day of Tuberculosis. While shadowing and helping the EHPV in Ida-Virumaa, I was able to learn about the cultural understandings and perspectives of the challenges faced by people living in Ida-Virumaa, the difficulties that PLWHIV face in Ida-Virumaa and the many challenges faced by the EHPV.

In addition to working alongside the EHPV staff and volunteers, participant observation was also conducted within each of the communities. The multiple weeks spent in each of the communities enabled me to gain an understanding about the life, economies, and difficulties faced and experienced within each community. It also enabled me to speak with locals, learn even more about the community, and the differences between the three communities. For example, during the three weeks in Narva, I never once heard Estonian spoken anywhere except on a television or radio, yet during my first evening in Kohtla-Järve, I heard Estonian and Russian both being spoken at a local grocery store.

As an ethnographer it was very important that the people I interacted with were aware that I am actively conducting research while in the community. To ensure my research was ethical, I told everyone I met that I was an ethnographer conducting research on HIV stigma, and that I was interested in speaking with him or her. I also informed them that if there is something they do not wish me to include in my research they could inform me and their requests would be respected.

### **Sampling**

Prospective participants were recruited completely in collaboration with the EHPH's regional staff members, and snowball sampling was used to recruit prospective participants. Snowball sampling is a chain referral method of sampling that begins with a small group of key informants who either refer the researcher to potential participants and/or refer prospective participants to the researcher (Bernard, 2011, p.147). Once this first wave of participants met with the researcher, the researcher asks them to refer him or her to other prospective participants. This process continues until the researcher is able to recruit enough participants that the data becomes saturated, which is when the recruitment of more participants will not necessarily add more value to the data already collected from previous participants.

In this study, the EHPV staff members approached their clients and informed them about the study. Because PLWHIV in Ida-Virumaa are marginalized individuals and the time constraints of the study, the Board of the EPHV thought it would be more effective if EHPV staff acted as a gatekeeper between prospective participants and myself. Acting as a gatekeeper, the EHPV was able to inform and ensure perspective participants about the goals and benefits of this study. This also ensured that the

participants were able to decide whether to participate in this study from a previously established relationship of trust. Moreover, because my time within the each community, EHPV staff members also reached out to different healthcare providers and invited them to partake in the study. Prior to and during participant recruitment, I worked beside EHPV to ensure a balance of the demographics of the sample, but the EHPV staff members handled all contact with the prospective participants.

The sample consisted of 11 interviews ( $N = 11$ ), which included eight semi-structured interviews with PLWHIV and three unstructured interviews with healthcare providers who were not HIV positive. Although ten semi-structured interviews were conducted in the field two interviews were removed from the sample. One of these interviews was removed because it was a very short and limited interview, while the other was removed because of ethical reasons that arose during the interview. Nevertheless, the eight semi-structured interviews selected for analysis were sufficient to ensure saturation of the data. Recruiting healthcare providers to participate in the study was very challenging due to the time limitation in each of the different communities, and as a result, saturation of the data did not occur in the unstructured interviews. However, the testimonies from the healthcare providers added valuable, supplemental data to the semi-structured interviews, which was valuable in qualifying the experience of PLWHIV in Ida-Virumaa.

The demographic information of the study is presented in Table I, participants are referred to by pseudonym only. All semi-structured interview participants signed an informed consent (See Appendix III) form, which described that they would be reported in the data by a pseudonym and the name of the community where they live: either Narva



or Kohtla-Järve and Jõhvi. The unstructured interview participants signed a similar informed consent form, but were reassured that where they live or work will not be disclosed as doing so could result in their identification and loss of employment. As research progressed it became apparent that some of the participants could be easily identified by the combination his or her demographic information, profession, and the community by naming the community where he or she lived. As accidental disclosure of this information, could result in serious negative impacts on a few of the participants, I decided during data analysis not to identify the communities where participants lived. The only exception to this case is Olga<sup>13</sup>, but the disclosure of where she lives and her current profession does not threaten a breach of confidentiality or risks unintentional disclosure of her identity and HIV status.

Of the eight semi-structured interviews selected for analysis, 5 participants were female and 3 were male. The mean age of the sample was 35.5 years old, and participant age ranged between 32 and 47 years of age. The sample equally represented the areas of Narva, Kohtla-Järve and Jõhvi, as 4 interviews were selected from Narva and 4 were selected from Kohtla-Järve and Jõhvi. As Kohtla-Järve and Jõhvi are in very close proximity to each other and share the same healthcare centers (hospital, methadone clinic, *infectionist* offices and ART centre) they were considered to be a part of the same region for the purpose of this study. All of the participants have known about his or her HIV positive status for more than five years, meaning that none of the participants were recently diagnosed with HIV. Three of the participants actively use intravenous drugs, three of the participants have a history of intravenous drug use but are no longer using

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<sup>13</sup> The story of Olga's life of growing up in Narva is used in the following chapter to build a context of understanding about the difficulties faced by PLWHIV in Narva, Ida-Virumaa, and Estonia as a whole.

drugs, and two female participants had no history of drug use. All of the male participants had a history of intravenous drug use, but only one is currently using intravenous drugs. Two of the participants provide healthcare services to PLWHIV, two participants work in construction, one is currently actively searching for working, and three where stay-at-home mothers.

Table I  
Sample Demographics

Participant's Name	Gender	Age	Years Living with HIV	Marital Status	Profession	History of Drug Use	Active Drug User	Adherence to ART
<i>Semi-structured Interviews</i>								
Constantine	Male	32	11	Single	Construction Worker	Yes	No	Adherent
Marianna	Female	32	8	Married	Stay at home mother*	No	No	Adherent
Nadia	Female	37	14	Married	Nurse	No	No	Adherent
Natasha	Female	46	14	Married	HIV peer-counselor	Yes	No	Adherent
Olga	Female	32	17	Married	Stay at home mother*	Yes	Yes	Non-adherent
Peter	Male	33	12	Single	Unemployed	Yes	No	Adherent
Svetlana	Female	32	16	Divorced	Stay at home mother*	Yes	Yes	Non-Adherent
Victor	Male	39	12	Married	Construction Worker	Yes	Yes	Adherent
<i>Unstructured Interview</i>								
Anastasia	Female	48	NA	Married	Nurse	No	No	NA
Daria	Female	32	NA	Single	Social Worker	No	No	NA
Valentina	Female	32	NA	Married	Social Worker	No	No	NA

All of the participants were ethnic Russians either from Ida-Virumaa or moved to the region when they were very young. This study was open to the inclusion of ethnic

Estonians and tried to include ethnic Estonians into the research. However, because the population of Ida-Virumaa predominately consists of ethnic Russians, and that the majority of PLWHIV/AIDS in Ida-Virumaa are ethnic Russians, the research team was unable to recruit an Estonian participant to partake in the study.

Three unstructured interviews were conducted, and all three participants were female healthcare providers or service providers who provided services to people living with HIV/AIDS. To protect the anonymity and confidentiality of these individuals, the details of where they work and what city they lived will not be shared. However, to speak of healthcare or HIV service providers as a whole, including those who participated in the semi-structured interviews, two social workers, two nurses, and one HIV peer-councilor participated in this study. Each of these participants provides services to PLWHIV, and three work directly with ART. The inclusion of the healthcare providers into the study, especially those who were also HIV positive, provided an important means to gain an insight into how healthcare providers viewed the themes presented by the participants who were living with HIV. The combination of these two points of view were essential to both gain a less-biased perspective of how stigma influences care seeking behaviour for PLWHIV, and to obtain a more complete picture of the challenges facing PLWHIV in Ida-Virumaa.

### **Research Procedure and Ethical Considerations.**

This study involved engaging and working alongside an extremely vulnerable and marginalized population in a marginalized region of Estonia. Extreme care was taken during the interview process and participant observation to ensure that the participants were not physically, psychologically, socially or economically harmed. The identities of

the participants were kept confidential at all times. Although EHPV staff members facilitated the recruitment of the participants, opinions and testimonies of the participants were not openly shared with EHPV staff members. On occasion, it was necessary to approach EHPV staff members to ask for further insight and understanding about an issue or idea raised by a participant. When this occurred, EHPV staff members did not know and were not told which participant shared the idea or issue.

Gaining entry to the field was not an easy task, and required extensive preparation developing connections and a relationship with the EHPV, and gaining an understanding of the historical, political, economic, social, and cultural context of Estonia and Ida-Virumaa. Prior to beginning the study, I traveled to Tallinn to meet with Lastin Alijev, the regional director of the EHPV. Mr. Alijev was very open to supporting this project on the conditions that I examine all three communities<sup>14</sup>, provided the EHPV with a report of the findings, and if possible return to Estonia at a future date to present my findings to the EHPV. Mr. Alijev and the EHPV agreed to facilitate the study, aid in the recruitment of participants and research assistants and allowed me to shadow the EHPV regional director for Ida-Virumaa, Elena Antonova, who became my principle gatekeeper for the study. In return, I would provide the EHPV with reports based on the findings of the study. Because of the geographical location and ethical concerns of PLWHIV in Ida-Virumaa, ethics approval for this study was obtained from two distinct research ethics boards: the UNBC Research Ethics Board and the Tallinn Medical Research Ethics Committee.

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<sup>14</sup> Prior to this meeting with Mr. Alijev, this study was going to be conducted only in the city of Narva.

### **Entering the Field.**

I arrived in Narva on the 7<sup>th</sup> of February 2016, and spent my first few day in the field learning about the community and the location of important public and commercial centers including the public library, different shopping centers and important landmarks. I first met with Mrs. Antonova on February 10<sup>th</sup> 2016 to discuss the research design, inclusion criteria for participants, job requirements for local research assistants, and learn more about Narva, Ida-Virumaa, HIV and PLWHIV in the city. She and other EHPV staff began reaching out for interview participants that day, and interviews in Narva began the following week.

The pre-interview process was slightly different depending on the participant. If a participant was either an active intravenous drug-user or very nervous about the interview, he or she would first meet with an EHPV staff member, who would conduct his or her own work with the participant and ask about the general health, mental state, and if the participant was under the influence of narcotics or alcohol, before bringing him or her to the interview. This procedure acted as a means to build trust and rapport with the participants and as a safe guard to ensure that participants could ethically provide informed consent. Participants who felt comfortable with the interview and did not have issues with addictions were allowed to come to the interviews without first having to meet a staff member of the EHPV. At the beginning of each interview, participants were formally greeted, which included the shaking of hands and taking of coats, and we engaged in small talk as a means to build and establish rapport and to see if the participant was physically and mentally able to participate in the interview.

Each participant was presented with the study description and informed consent form (Appendix IV). Prior to giving the informed consent form to the participant, I asked the participant basic demographic questions, which included the questions if the participant currently struggles with addictions and if he or she was currently under the influence of drugs or alcohol. Once given to the participants, all sections of the informed consent form were individually discussed with the participant and all questions were answered prior to the participant signing. Upon the completion of the interview, each participant received a €10 gift card for the Sever supermarket chain, which had a store located in each of the communities, as an honorarium for their participation in the study and were asked to sign a form saying that they received the honorarium.

In addition, permission to audio record the interviews were gained during the informed consent process. Digital recordings were transcribed verbatim in Russian by a team of local research assistants. These transcripts were randomly assigned to different research assistants. Due to the study location, budget limitations and time constraints, it was not possible to locate and hire professional transcribers for this task. Instead, with the EHPV's aid, local individuals who had experience transcribing were hired and trained. Because my accent may have made it difficult for participants to understand, one of the research assistants also helped me conduct the first set of interview in Narva to ensure that the participants and I correctly understood each other. After the first few interviews, I was able to effectively conduct the interviews by myself and no longer needed the assistant's help. To ensure the quality accuracy of the transcriptions, the research assistants and I regularly checked each other's work. Once transcribed into Russian, the digital files of the interview transcriptions were hand-delivered to an

additional research assistant who translated each interview from Russian into English. Each of the research participants signed a confidentiality agreement (Appendix V) prior to either gaining access to the data or meeting a participant.

Tea, coffee and a food, either a small box of chocolates or a box of cookies, were also prepared and served to the participants in each interview. In addition to being polite, serving people tea and inviting people for tea is a very important cultural practice in Russian culture. The purpose of preparing, offering and serving tea to the participants was initially done to aid in establishing rapport with the participants and facilitate small talk, but it also resulted in an unintended effect during the interviews. The participants were often surprised when I offered them tea or coffee, and EHPV staff members were perplexed when they learned of it. As I later learned, by shaking the participants hands before and after the interview, by taking their coats and by offering tea, I was not only being polite and engaging in Russian cultural norms, I was also unwarily communicating to the participants that: “I know you have HIV, but I see you as a fellow person, an equal. I do not fear you, and I respect you for who you are.”<sup>15</sup> PLWHIV in Ida-Virumaa are marginalized and feared, and by doing these simple acts, I was able to establish an unexpectedly positive and candid rapport with each of the participants.

### **Data Collection.**

Interview data was collected through the use of open-ended questions of the interview guides (Appendix I and II). Although each of the interviews used a previously created question guide, these interview guides were designed to facilitate discussion not confine it. Participants were encouraged to openly share their ideas, perspectives and

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<sup>15</sup> The cultural significance of these actions explained in detail in the Results Chapter.

experiences related to a specific question or theme that was being explored. Participants were only politely interrupted if they began to significantly deviate away from the questions and themes of the interview. During the interview, notes were taken regarding the participants' responses, intonations, and body language. A reflection was also written after each interview to discuss the interesting themes or ideas that emerged from the interview and to identify any areas of the interview process that could be improved.

The interviews ranged between 90 and 125 minutes, which provided the participants and I adequate time to explore both the questions being asked and unexpected themes that would emerge from the interview. Because this study is both ethnographic and exploratory, the participants' responses to certain questions were not predictable, and as new themes emerged during the interview, such as anger towards doctors, questions about these themes were asked to the participants in following interviews. Although an interview guide was created prior to entering the field, many of the questions asked during the unstructured interviews were based on themes that arose during the semi-structured interviews. This was done to gain an understanding about how healthcare provider's specific issues brought up by the participants who were living with HIV.

In addition to the interviews, I actively and regularly recorded field notes about my observations of the communities and information shared with me by Mrs. Antonova and other staff and volunteers of the EHPV. These field notes aided in obtaining an understanding of life in three communities Ida-Virumaa and the challenges faced by PLWHIV. In addition to providing a means to collect vast amounts of information and data, field notes were analyzed in the field to build a context around the interview



questionnaires and identify questions to ask future participants, EHPV staff members, and healthcare providers I would meet in the field. Local and national newspaper articles were also collected and analyzed in the field to further facilitate an understanding of the issues facing Estonia, Ida-Virumaa, and PLWHIV.

The daily recording and analysis of field notes, interview reflections, and media discourse were necessary to obtain an emic understanding of the experiences and perspectives of the participants. They also provided an important means to separate my own perspectives from the data and focus on those of the participants and examine how they shared their thoughts. This process was taken at all stages of the research to ensure that my etic perspectives, or those of an outsider, would have a minimum influence on the emic perspectives of the interview participants and the people I met in the field.

One of the challenges facing anthropological, ethnographic and other forms of qualitative research is that a researcher's own worldview may result in the misinterpretation of testimonies or observations collected in the field. Because the researcher's etic (outsider) perspective of a phenomenon may vary from the emic (in-group) perspective, the researcher's experiences and interpretations are subject to bias. Moreover, a researcher's own experience and worldview may influence what data they collected and who they are willing to speak with in the field. To help reduce this potential internal bias, ethnographic researchers often use reflexivity. Reflexivity is a qualitative method of self-reflection that entails the constant awareness, assessment, reassessment by the research of his or her own contribution, influence, and shaping of intersubjective research and how his or her own perspective will influence the research findings (Salzman, 2002, p. 806). Self reflection and understanding of how the researcher's self is

related to the participants and community of interest provides an important means for the researcher to learn how and why he or she collected the data, and more truly understand that data, so he or she can better represent the perspectives shared by the participants (Salzman 2002, p.808).

As for myself, reflexivity was extensively used prior to entering the field, while in the field and during data collection. During my undergraduate degree, I learned the importance of obtaining the emic perspective and how the one's etic perspective presents a significant challenge to understanding how another individual or group sees and understands the world. This understanding and appreciation of the emic perspective was further developed while I lived in the Russian Federation, and Japan, and worked alongside individuals from very distinct cultural backgrounds. During these lived experiences and through studying multiple languages, I learned how different cultures communicate and the importance of striving to understand the worldview of a particular culture because accurate meaning and understanding cannot always be accurately translated or interpreted.

In addition to these lived experiences, I have extensive experience living in the Russian Federation and have a very clear understanding of Russian culture, worldview, economics, politics, history, and became very fluent in Russian. During the three different occasions when I lived in Russia, I spent most of my time in the cities of Syktyvkar and Vorkuta, which are communities similar to Narva, and Vorkuta has experienced similar economic difficulties since the 1990s as Ida-Virumaa. The combination of my knowledge and experience living in Russia and my understanding of the importance of the emic perspective of the participants enabled me to use reflexivity to

listen and understand the perspectives of the participants, gatekeepers and members of the community and ensure that their perspectives were accurately represented in the data.

### **Data Analysis**

Content analysis was used to analyze the data, identify the different themes and categories that emerged from the data and to create a means of understanding the symbolic meaning of these themes and categories. Content analysis is a flexible research technique used for making replicable and valid inferences from data and is characterized as method of inquiry into symbolic meaning of phenomenon within their context of use (Krippendorff, 1980, pp. 21-22). The aim of content analysis is to attain a condensed and broad description of the phenomenon being studied with the outcomes of analysis being concepts or categories that can be used to create a model or conceptual map describing the phenomenon (Elo & Kyngäs, 2008, p. 108). Symbolic meanings can be examined and understood from many different perspectives, and the meaning of symbols may not be shared between different individuals. For example, how a participant perceives and understands a specific symbol may be very different than how the researcher perceives or understand the same symbol (Krippendorff, 1980, p .22). Because of this possible difference of interpretation, content analysis emphasizes that the symbolic meaning of messages or a text needs to be analyzed while accounting for external factors that would or could influence the meaning of the text that include: event leading up to or surrounding when the text was first produced, location and time of when the text was produced, and the historical, political-economic, and socio-cultural context of when the text was written.

Content analysis can be used for both quantitative and qualitative research designs, though how it is used differs greatly. In quantitative studies, content analysis is a positivist and deductive research technique that is used primarily for hypothesis testing (White and Marsh, 2006, p. 30). Hypotheses are developed based on preexisting research and literature, and a coding system is clearly designed and implemented a priori to data collection. The themes, categories and concepts of the coded data can then be analyzed with a variety of statistical techniques including word frequency, key word lists, cross-tabulations, model development and other multivariate techniques (White and Marsh, 2006, p.32; Weber 1990). Similar to other quantitative techniques, content analysis strongly emphasizes the importance of validity and reliability. To ensure validity, a priori codes and categories must be generalizable beyond the specific data being analyzed (Weber, 1990, p. 18). Because different individuals may interpret symbolic meaning differently, particularly if the text is from a different location or time period, content analysis emphasizes that codes, categories and data need to be developed in a way that if different analysts were to analyze the same series of texts they would be able to produce the same findings (Krippendorff 1980, p. 23).

Content analysis is also commonly used as a qualitative technique. Where in quantitative studies content analysis is used as a deductive and positivist technique, it is used as a humanistic and inductive technique in qualitative analysis (White and Marsh, 2006, p. 34). Although an initial hypothesis and research questions are incorporated into the study design, qualitative content analysis emphasizes not only answering the pre-established research question or questions but also considers any transformation that the original research questions may have undergone during coding and any new codes or

themes that emerged from the data (White and Marsh, 2006, p. 39). Open coding is used to identify possible categories and themes during data collection and analysis. Open coding requires researchers to tediously read and re-read their data through to identify any themes, concepts, categories and/or patterns that emerged from the data (Elo and Kyngäs 2007, p. 109). These categories are then carefully scrutinized to identify any new patterns, categories or hidden meanings emerge from the previous categories and to identify the relationships between the categories. Careful reading and rereading of the data and categories enables the research to identify evidence that confirm his or her emerging construct while at the same time identifying evidence that can disconfirm the emerging construct (White and Marsh, 2006, p. 37).

Coding began in the field through reviewing field notes and experience during participant observation, and reflecting on interviews. During this time, three prominent themes related to accessing care emerged during data collection: perspectives of HIV Stigma fear of disclosure and bad experiences and discrimination from healthcare providers, and reasons for non-adherence to Antiretroviral Therapy (ART). These overall themes were experienced and expressed by all of the participants in the semi-structured interviews and had significantly impacted their willingness to access care, particularly in Narva.

Manual coding of the semi-structured interviews began after all of the interviews had been transcribed in Russian and translated into English. Two different coding methods were utilized for the first stage coding: attribute coding and structural coding. Attribute coding was used to create profiles of each of the participants. Information coded in attribute coding included demographic information regarding each participant as well

as some information regarding the participants' life history, history with HIV and experience with HIV. Structural coding was selected for the first phase of data analysis because this research is exploratory and incorporated a standardized semi-structured interview guide for the semi-structured interviews. As a method of analysis, structural coding uses a list of codes that are derived from the research questions to initially categorize and code the data to enable the examination of comparable segments, similarities, differences and relationships that enabled me to quickly access data related to a specific category (Saldaña, 2013, p. 84).

The initial structural codes and categories used in the first phase of coding were: *Perspectives on HIV*, *Accessing Care*, *Perspectives of ART*, and *Living with HIV*. Four additional categories that emerged during data collection and included in this stage of the analysis were: *Fear of Disclosure*, *Perspectives/Discrimination by Healthcare Providers*, *Reasons for Non-Adherence*, and *Sense of Change*. To explore other possible barriers to care and perspectives of HIV and HIV stigma, three additional categories were included in this phase of the analysis, *Estonia vs. Russian perspectives of HIV*, *Perspectives of HIV and People Living with HIV in the Russian Federation*, *Estonians vs. Ethnic Russians*. To meet the requests of my research partners, the Estonian Network of People Who Live with HIV, an additional category was created titled *EHPV* that examined how people viewed and valued the EHPV and the services they provided.

The methods used for coding the unstructured interviews were the same as those used for the semi-structured interviews. Attribute Coding was used to code each of the three participants demographic information and experience with HIV and PLWHIV, and a pseudonym into a brief profile. Structural Coding was used to create codes/categories

that were based on the studies research questions and some that emerged from the data. These codes/categories include: *Perspectives/ Discrimination by Health Care Providers, Perspectives of HIV, Perspectives of Reasons for Non-Adherence to ART, Accessing Care, Promoting/Perspectives of ART, HIV in Estonia, and Life in Ida-Virumaa*. Although some of the categories created in this first phase of coding are similarly named as those in the semi-structured interview, the codes/categories of the unstructured interview shows the perspectives of healthcare and HIV service providers. Moreover, the data of the unstructured interview was used to supplement the perspectives expressed in the semi-structured interviews.

First phase coding identified and organized a substantial amount of data from the semi-structured interview, the unstructured interviews and the field notes. Second phase coding focused on the analysis the first phase categories of: *Perspectives of HIV, Accessing Care, perspectives and discrimination from healthcare providers, living with HIV and fear of disclosure*.<sup>16</sup> These categories were then analyzed and reanalyzed individually and then as a collective whole. This was done to ensure accuracy of the themes that emerged from each category and to see how the different categories influenced each other. To ensure the accuracy of themes that emerged from the data, I regularly approached staff of the EHPV, research assistants, my Russian wife, and my Russian friends and asked them to explain to me the cultural meanings of specific data-points and themes. Because many of the themes identified in the data did not easily translate into English, seeking consultation ensured the data would be accurately interpreted and represented in the analysis.

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<sup>16</sup> The analysis of all the categories and identified with first stage coding went beyond the requirements of a Masters Thesis. However, the information regarding reasons for Non-adherence to ART will be published in a report and submitted to the EHPV. An article on this topic will be also submitted for publication.

The triangulation of the four different research methods enabled a more complete understanding of the meaning HIV and how HIV stigma influences the daily life of PLWHIV. By interviewing both PLWHIV and healthcare providers who provide services for PLWHIV, concise metaphors of HIV emerged from the data, and many of these metaphors were shared by both groups of participants. Moreover, participant observation and media discourse analysis provided an invaluable means for contextualizing the meanings of HIV and HIV stigma with the life and challenges PLWHIV face in Ida-Virumaa.

The triangulation of methods, the effort taken to ensure the accurate interpretation and representation of the data from the original Russian transcripts, reflexivity, and level of care incorporated into the interview process ensured that rigor of the study met the criteria provided by Lincoln & Guba (1986). Careful research design and triangulation of methods enabled the collection of a large and concise pool of data that ensured the dependability of the study. As the population is fairly representative of ethnic Russians living with HIV in other post-Soviet countries and the level of detail collected in the study, Lincoln and Guba's (1986) criteria for transferability are met. The following chapter will explore the themes that emerged from that data and provide a detail analysis of how they influence the daily lives of PLWHIV.



## **Chapter Four: Results**

This chapter examines the perspectives and barriers to care for PLWHIV in Ida-Virumaa that emerged from the content analysis. Quotes and testimonials from the participants are provided to illustrate their stories and experiences and to build a context for understanding how HIV stigma and discrimination not only hinders their daily lives, but also makes accessing care extremely difficult. It begins with a narrative of the difficulties one of the participants has experienced and continues to experience living with HIV in Ida-Virumaa, before proceeding to the analysis and discussion of the different themes that emerged from the data.

### **Olga's Story**

Olga was born in Narva and grew up during the political, economic and social chaos that characterized the fall of the Soviet Union and Estonia's transitional period. Now in her early thirties and a mother of three, Olga has lived and continues to live through many of the challenges faced by people living with HIV in Ida-Virumaa. Possessing a razor sharp wit and an attitude that cries, "I don't care what others think", it is hard not to be inspired and impressed by Olga's personality and cheerful laugh. Her personality, however, has been greatly influenced by her experience as a person living with HIV, and her story is as much about Ida Virumaa's HIV epidemic as it is about her.

Like many others of her generation, Olga began using intravenous drugs in her early teens. The political and economic transition of a post-Soviet Narva was not only characterized by the closures of factories and increasing unemployment, but also by the closure of youth centers, which limited the activities that existed for children and youth.

The lack of opportunities and activities available for children and youth meant that they had little to do while not in school, and they became the unfortunate targets of drug dealers. In 1999, after years of intravenous drug use, Olga learned that she was HIV positive. Having heard only horror stories and myths about HIV, Olga, who was pregnant at the time, was very upset, disturbed, and terrified upon learning about her HIV positive status and what it would mean for her unborn child. Unfortunately, nothing prepared her for what was about to happen. Turning to her doctor, she asked, “What can be done?” The doctor simply answered, “*Idii domoi i zhdii, kogda umryosh!* (Иди домой и жди, когда умрёшь!)<sup>17</sup>,” which translates as, “Go home and wait until you die!” Olga would not receive any care or treatment for HIV from a doctor for another five years.

Understandably, Olga’s life changed when she learned about her HIV status. It began with a sense of fear that she had very little time to live.

By the time I found out, it could not get any worse. Actually, all people know that they will die someday, and those who use drugs are bringing this day closer by using drugs. But when you learn that you have HIV, you realize that you may not die in a month, but tomorrow. It is scary. Of course, I was scared for some time, but then a week passed, two weeks, a month, then a year. Nothing changed. Everything stays the same. Nothing hurts, and it gradually goes away. The fear stays of course, but it recedes into the background. You know about it and remember about it, but you do not dwell on it when you do not feel any physical changes in your organism. They said, “It is AIDS. You will die tomorrow.” This is what we were told in the beginning.

The combined shock of the diagnosis and the doctor’s response left Olga both afraid and perplexed. Having been told that there was no hope for her future and without a proper understanding of HIV biology, Olga even more lost than she was before. Especially as

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<sup>17</sup> Throughout this chapter, results are sometimes presented in English, Russian, and the Romanization of the Cyrillic alphabet. This is done to identify key phrases and words used by the participants, to aid in accurate translation of the meaning of these words and phrases, to provide the original words used by the participants, and to aid readers not fluent in Russian in understanding the original source. The ICAO system for Romanization of the Cyrillic alphabet was used.

she was uncertain and terrified about how her HIV diagnosis would affect her unborn child.

As time passed, Olga became less concerned with the health issues of HIV, as the stigma associated with HIV and PLWHIV began to greatly affect her daily life.

[People] dash away from us....I think that maybe people are scared of [HIV]. Maybe they are afraid that HIV will come into their families and are afraid of getting infected themselves. Even though there have been many talks about it, people are still not ready to accept HIV-positives, and consider them as full-fledged members of society. They think that such people have to be isolated from those who do not have HIV. They can exist, but somewhere separate from others...even though not half but a quarter of Narva's population is HIV-positive. There are a lot of such people in Narva and it has affected every family, and they have faced this problem...When some of my friends' parents learned about [their HIV status], they were kicked out of the house and told, "Don't come here anymore". Some, like my mother, have not changed their attitude. I did not have a [friend or family member] who turned their back on me. Maybe because I am a woman and a woman does not get a handshake when she is greeted. But the men have such experiences. There was even a situation when a [friend of mine] did not receive a handshake [from his friends] while I was standing next to him, even though they had known each other for a very long time. [His friends] had learned that he had HIV, so he was not worthy of a handshake. This is all a fear of getting infected and people are afraid of that, and do not want to accept it.

The powerful stigma associated with HIV and PLWHIV forced Olga to hide her status from all except her closest friends. She continues to have very strong fears that the accidental disclosure of her status will result in negative social consequences not only for her, but for her family and children.

Even if there are people who know [about my status] among those whom I would not want to know, they simply do not communicate with me and do not see me. I do not know, and honestly, I would not want them to know because I am afraid that they would treat me differently. I am afraid of becoming a castaway. Although I am telling you, here in Narva [PLWHIV] can be found on every corner...people still try to shield themselves from us. They do not want to be near us one way or another. They do not even want to briefly meet with us.

In Ida-Virumaa, it is very common for young adults to share an apartment with their parents, grandparents and extended family. At the time of her diagnosis, Olga was living with her mother and sister, and she tried very hard to hide her status from her family. However, five years after being first diagnosed, her mother accidentally learned of her status when she was going through some open mail that was left on a table. Upon learning of Olga's status, Olga's mother asked Olga if she understood what the letter meant, and Olga replied that she did. Her mother did not get upset, or angry, but she did tell Olga that she would need to have her own dishes, cups and towels, and that they needed to be kept separately from the rest of the family's. This initially caused Olga a lot of emotional pain as she felt that she was now different from and a danger to the rest of her family, "The only thing is that she was worried for her other children's health. What if I infected them through the dishes or through the towels? She assumed that and she put everything away." Soon thereafter, Olga and her mother visited an HIV clinic in Narva to learn more about HIV. Having both learned more information regarding HIV transmission, they returned home and her mother put Olga's plates and towel back with the rest of the family's.

Although Olga was not forced out of her family when her mother learned of her status, it was still a very upsetting experience for her, as she would have preferred that her mother never learned about her HIV status. She has still not told her mother-in-law about her and her husband's HIV positive status because they feel very strongly that they would become outcasts from her husband's family. This fear of becoming outcasts is held not only towards Olga's in-laws but also towards her extended family. Describing this fear, Olga said,

I do not know what would happen if they found out. Probably, I am afraid that if they found out, they would turn their backs on me. Not just from me, but from my mother, brother and sister as well. Maybe, I am afraid that this will not only concern me but my closest circle [as well]...I do not wish to tell them, and actually I do not see any sense for anyone to know except for close relatives: mother, father, brother and sister.

The combination of the negative perspectives of PLWHIV and the fear of others learning about her status has made life very challenging for her. Olga not only had to worry about the social consequence that could happen if she and her husband were to be identified as having HIV, but they also need to worry about economic consequences, as either them could loose their jobs if their HIV status became public knowledge.

Unfortunately, accessing and receiving adequate care has also been a very difficult and emotional experience for Olga. As mentioned earlier, Olga only began receiving treatment and support for HIV five years after her initial diagnosis, when she was pregnant with her first child in 2004. At the time, Olga had already been living in Tallinn for a few years, and after hearing about the difficulties some expecting mothers, who were also HIV positive, faced trying to find doctors to oversee their pregnancy, Olga decided to be very open about her status when looking for a doctor.

When I was going to women's consultation with my first pregnancy in Tallinn, when I was entering doctors' offices, I was telling the doctors that I had HIV. I asked "If they would work with me, I would stay. If you are uncomfortable, I will find another doctor." Two doctors told me, "Young woman, you are in the wrong office." They refused me. So I went to a third doctor...I do not know why [they said no] it was all in the same [maternity hospital]...[but] I went to the [third doctor] and she treated me well. My pregnancy was going well and I had no problems with the doctor. But when the time came to deliver, I felt that she had masterfully been hiding her bad attitude towards me. In Tallinn, the system is that the doctor who works with you during pregnancy delivers the baby as well...I was to have a C-section. The doctor who had been [overseeing] my pregnancy was going to do the operation. Then, I understood that she was not eager to deliver the baby, maybe because it was a big risk, a risk to touch the blood, and she was not happy with that. She was Estonian. In the last moment before the

surgery, when I had already been taken to the operating room, she said such an unpleasant phrase that I wanted to get up and leave. “Came here from Ida-Virumaa? Don’t you have another place to deliver babies?<sup>18</sup>”... This phrase is still in my head. It happened 10 years ago, but I still remember the look on her face...I still have a bad feeling about this, that she had not said anything before...I wanted to hurt her too. It was all so strange, because I asked her from the very beginning if she would be willing to work with me. And she said that it wouldn’t be a problem.

Unfortunately for other expecting mothers living with HIV, such behaviour from healthcare professionals was not uncommon. Olga shared a similar experience of one her friends who was trying to receive care while pregnant in Ida-Virumaa.

She had been sent for a check-up including HIV. When the doctor learned about HIV from the blood test, the girl confessed that she had known about her status before visiting him. The doctor treated her with negativity and grievance. The doctor asked why she did not say anything before and why they had to learn from the test. The staff’s attitude changed immediately. My friend stood up from the chair and the nurse immediately started to disinfect it. She was ordered to bring her own cushion, and they always put another one under it. She was even given a different pen to make a signature. In so doing, only drug addicts would remain infected, and so it was. And the doctors thought why would drug addicts have children? ... The attitude was the following: you are a drug addict and a HIV positive or vice-versa. Generally, one made the other worse.

It is important to note that the previous experiences that Olga shared took place between 2004 and 2010, during the early years of Estonia’s HIV epidemic. Unfortunately, despite the time that has passed since the beginning of the epidemic in the early 2000’s, Olga still experiences discrimination from healthcare professionals when she accesses care. In 2015, during her most recent pregnancy, Olga went to visit a gynecologist to oversee her pregnancy. Upon learning about her HIV status, the gynecologist condescendingly asked her, “You do understand what kind of baby you will have?” With the strong belief that

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<sup>18</sup> The doctor’s quote was discriminating Olga not only because of Olga’s intravenous drug use and HIV positive status, but also because Olga is an ethnic Russian from Ida-Virumaa, who was living in Tallinn. As the doctor was Estonian, this quote emphasizes the ethnic tensions between the Estonian majority and ethnic Russian minority and the stigma Estonians and ethnic Russians not living in Ida-Virumaa have towards the people of Ida-Virumaa.

doctors think PLWHIV and drug users should not have children, Olga replied, “I understand. I have two children that are completely, healthy children, so I understand why I am having a third baby.” Again with a negative condescending tone, the doctor replied, “Well that is your business.”

The combination of multiple experiences of discrimination from healthcare professionals and community members, along with living with HIV for 16 years has made Olga more immune to the negative comments and slurs directed at PLWHIV and the remarks of health care professionals. And despite 15 years passing since the beginning of Estonia’s epidemic, Olga still encounters discrimination every time she tries to access care or receive antiretroviral therapy. The only full time *infectionist* in Narva has an office located in the Narva Central Hospital. The office has an entrance where anyone who enters will be easily seen and identified by other people in the hospital. This means that if a person enters that office, anybody looking on will understand that something is wrong with that person. More specifically they will assume that the person has HIV. Olga has overcome her previous reservations of accessing care in this office, but insists that it deters many others from doing so.

I think there needs to be a separate entrance [to the clinic]. In the town hospital, people can still see. There is a big hall, and I have to pass through it to go to this unit. And everybody can see me with my baby. They look down on me. But I am an experienced mother. I do not care ... but many people prefer not to go because someone can see or know that they went to the infectious disease doctor’s office...a lot of people do not go to the doctor or receive therapy because of that. They are afraid to be seen and [word of their status] will spread and negatively affect their lives.

Despite living with HIV for more than 15 years, Olga still struggles when seeking and accepting care from health care providers. Except for during her pregnancies, she has never properly adhered to antiretroviral therapy and does not intend to do so. Despite the

benefits that ART would provide her, it should not be surprising why she no longer listens to or trusts doctors and other healthcare professionals. Years of being talked down to, insulted, discriminated against, and provided misinformation has left Olga skeptical, and she strongly believes that some healthcare providers are not interested in helping her. Unfortunately, the other participants of the study had also lived through similar experiences. This implies that Olga's experiences and perspectives are not an isolated incident but an occurring phenomenon that has and continues to impact the lives of PLWHIV in Ida-Virumaa and prevents them from accessing care.

### **Introduction to Analysis**

Olga's life experience identified some major issues that PLWHIV face in Ida-Virumaa. Her story illustrates three theme clusters that were identified as barriers to care for a person living with HIV in Ida-Virumaa. The first of these themes is the very powerful stigma and cultural metaphors associated with HIV and PLWHIV that is given force by misunderstandings and lack of knowledge of HIV etiology and transmission. Furthermore, perspectives of HIV stigma and misconceptions about HIV are not only confined to the general population of the Ida-Virumaa, but are also shared by healthcare professionals. The second theme that emerged was that PLWHIV in Ida-Virumaa are very afraid of others learning about their HIV status to such an extent that they are very careful of where they go to receive services and will avoid accessing care all together if they feel there is a chance their HIV positive status could be unintentionally disclosed. The final theme that emerged from the data is that healthcare providers also act as a



barrier to care, as many PLWHIV do not wish to access care because of the behaviour, attitude and discrimination exhibited by healthcare providers.

The rest of this chapter will examine and discuss these three separate, yet interconnected, categories or theme clusters. Each theme cluster will be presented individually and the theme and subthemes of the cluster will be presented and discussed. It is important to remember, that although all of the subthemes and factors of barriers to care may not have been shared by each of the participants, the theme clusters themselves were strongly represented in all of the interview transcripts and in the observations and field notes.

## **HIV Stigma**

Perceptions and understanding of HIV play a serious role in the daily lives of the participants in the study as the perspectives of HIV have and continue to influence their care-seeking behaviour. This theme cluster consists of two themes each with its own set of subthemes. The first of these themes, *Perspectives on HIV*, details the participants' perspective of how the general public see and understand HIV and contains four distinct subthemes: (a) Cultural understandings of HIV Etiology and myths of transmission; (b) HIV means Death; (c) Fear of HIV, and (d) Apathy to HIV and the HIV epidemic. The distribution of these different themes within the semi-structured and unstructured interviews is presented in Table II. The second theme, *Perspectives of People Living with HIV*, presents the ideology through which the participants felt the general public viewed PLWHIV. This theme contains four distinct subthemes: (a) *Spidoznii is Narkoman*, (b) PLWHIV are less than Human, (c) PLWHIV are Not Worthy to be in Society, and (d) *Sam Vinovat*. The results of this theme are presented in Table III.

Table II

Summary content analysis for Perspectives of HIV shared by interview participants

Participant	Subtheme 1 Misconceptions of HIV and Myths of HIV Transmission	Subtheme 2 HIV means Death	Subtheme 3 Fear of HIV	Subtheme 4 Apathy
<i>Semi-structured interviews</i>				
Constantine	X	X	X	X
Marianna	X	X	X	
Nadia	X	X	X	X
Natasha	X	X	X	X
Olga	X	X	X	
Peter	X	X	X	
Svetlana	X			X
Victor	X	X	X	X
<i>Unstructured Interviews</i>				
Anastasia	X		X	X
Daria	X	X	X	X
Valentina	X	X	X	

Table III

Summary of Content Analysis for Perspectives of PLWHIV

Participant	Subtheme 1 <i>Spidoznii is Narkoman</i>	Subtheme 2 PLWHIV are Less than Human	Subtheme 3 PLWHIV are Not worthy of Society and Should be avoided	Subtheme 4 <i>Sam Vinovat</i>
<i>Semi-structured interviews</i>				
Constantine	X	X	X	X
Marianna	X	X	X	
Nadia	X	X	X	
Natasha	X	X	X	X
Olga	X	X	X	
Peter	X	X	X	X
Svetlana			X	X
Victor	X	X	X	X
<i>Unstructured Interviews</i>				
Anastasia	X		X	X
Daria	X	X	X	
Valentina	X			

**HIV Stigma: Perspectives on HIV.*****Poor Knowledge of HIV and Myths of Transmission.***

Over the course of the data collection and analysis, I learned that there are some serious misconceptions in the public's shared understanding of HIV of Ida-Virumaa, and that these misconceptions are held by the general public, PLWHIV, and even by some healthcare providers. The first of these misconceptions is that the members of the general population, including PLWHIV and some healthcare providers, do not understand the difference between HIV and AIDS and/or do not differentiate the two.

I think that they [general public] would not tell the difference between HIV and AIDS because people do not understand. Honestly, I do not see a difference. (Nadia)

[People do not see the difference between HIV and AIDS] A lot of people say AIDS and not HIV, and I correct them [and say] there is a big difference. And they tell me, “What is different between AIDS and HIV. All the same. No difference.” People do not see the difference. (Daria)

The doctors establish their relationships with HIV-positives as though they were sick with AIDS, through this [perspective]. And it does not matter that a person is disabled, that he needs surgery, this does not matter at all [because] he was labeled “HIV”. (Natasha)

What is particularly interesting is that the majority of the participants identified that the non-distinction between HIV and AIDS was commonly held between the general population and healthcare providers, which implies a shared perspective of HIV and AIDS as being one and the same. It is important to note that none of the participants saw HIV and AIDS as being one and the same, but this is because all of them have either lived with HIV for many years and learned about it, or are healthcare professionals who have been taught correct information regarding the differences between HIV and AIDS.

In addition to seeing no difference between HIV and AIDS, it appears that there are commonly held myths related to how HIV is transmitted from one person to another. Although there seems to be a general recognition and understanding that HIV can be transmitted via blood contact or unprotected sexual practices, many experiences about the popular misconceptions, or myths, of how HIV is transmitted were shared by the participants. The myth that was most prevalent in the data was that HIV can be contracted through either physically touching a person who is HIV positive, or by touching something that a PLWHIV used, particularly cups, dishes, eating utensils and towels.

Only educated people can understand, communicate [with PLHIV] and drink tea [with us]<sup>19</sup>. But with some people it even comes to this: that you have to visit them and bring your own dishes because they are afraid of being infected.  
(Victor)

Others do not understand that this is not the flu and it is not airborne. And they do not understand that I will not fall apart in their hands if they give me a handshake or squeeze me a little bit tighter, and I will not die in their hands.” (Olga)

They should know that HIV spreads through blood and through sexual intercourse. This is the main thing. This is everything that a person should know, that it is not transmitted through the household. That [PLWHIV are] not dangerous, and that it is easier to protect oneself from HIV than from a cold.  
(Natasha)

They think that they might get infected if you shake someone’s hand<sup>20</sup>. People are afraid of everything and they are cautious. (Peter)

The idea that HIV can be transmitted through dishes and by touching someone who is HIV positive is related to the cultural metaphor of *microbii* (микробии). Despite being the Russian translation of microbes and microorganisms, *Microbii* is a Russian term used to describe general microorganisms that are harmful for human health, and is synonymous in meaning and usage with the English word “germs”. *Microbii* is a very commonly used term to describe the causes of different diseases and ailments, such as colds, flu, parasites and tuberculosis, and can surround a sick person like a miasma. Because HIV is also *microbii* there is a fear that it can spread or “leap” from one-person’s plate to another, or that no matter how hard a person tries to clean a cup used by a person living with HIV, the *microbii* will still be there and will spread across the other dishes and through the household.

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<sup>19</sup> Being invited for tea and having tea with someone is a very important Russian cultural practice for developing and maintain relationships within the community. Not wanting to invite someone for tea is also very culturally symbolic, and will be explained in the following theme: *Perspectives of PLWHIV*.

<sup>20</sup> Like having tea with someone, shaking hands is also a very important social practice among Russian men. Not wanting to shake hands with someone is also very symbolic of how one person will see another. The symbolic meaning of shaking hands and refusing to shake hands will also be explained in the following theme: *Perspectives of PLWHIV*.

The perspective that there is no difference between HIV and AIDS, and the myths of transmission that HIV can be contracted through physical contact or by coming into contact with something used by a person living with HIV, particularly dishware, was prevalent in the majority of the semi-structured and unstructured interviews and suggests that these myths are widely entrenched beliefs of the general population of Ida-Virumaa. Although these were two of the more prominent perspectives that emerged from the interviews, they only represent an aspect of the shared perspective, which is based on misinformation, held by the population of Ida-Virumaa towards HIV. During participant observation, healthcare providers who would meet with me and the staff and volunteers of the EHPV shared that they frequently struggle trying to provide correct information about HIV to people newly diagnosed and even those who have been living with it for many years.

During our interview, Natasha and I were discussing the misconceptions and shared perspectives of HIV held by people living in Ida-Virumaa. Although she is very grateful that hospitals and the EHPV now have more information to provide PLWHIV, she is still very upset about the amount of misinformation easily accessible to the general public.

It is illogical. If one wishes, he may Google “What is HIV?” [in Russian], and it will respond that there is no HIV. And then there will be a lot of stupid things like that HIV is a weapon of mass destruction, that it is a secret virus created by the Americans and so on. But there is nothing scientific. You will be able to find something if you have a wish, but you have to work hard for it. (Natasha)

The metaphors Natasha described have been previously documented in previous studies about HIV in Estonia, Russia, and the Soviet Union (Feshbach, 2006; Goodwin et al.,

2003), but that they continue to exist in a region that has been experiencing an HIV epidemic for over fifteen years is of great concern and it presents certain challenges to those who provide services for PLWHIV. During one of our meetings, Natasha told me that there are a lot of PLWHIV who do not accept or believe HIV or in their HIV status. One of the cases Natasha shared with me really demonstrated this refusal to believe in an HIV diagnosis. For a few years, Natasha had been working with a woman, in her thirties, and was trying to convince her to take ART for years. Natasha described that the women had history of intravenous drug use and because of her low immunity, large portions of her face, neck and back were constantly covered in herpes. When I asked her about why this woman would not take ART, Natasha simply replied, “She refuses to believe in HIV. She simply does not believe that HIV is real.”

### ***HIV is a Death Sentence.***

The second-sub theme to emerge from the data was the perspective that HIV is a death sentence. Through both the semi-structured and unstructured interviews, the participants shared a perspective that the general public views and understands that HIV means death (Вич это смерть/*VICH eto smerrt*), and that there is no cure or treatment for a person living with HIV.

Most people would say that if a person is sick [with HIV], he is dead; it is time for him to go to the cemetery. They may understand that there is treatment but they do not understand that you can live with the treatment for 10, 20, 30 years. I think that people think that PLWHIV have a 2-3 years maximum until life is over. Even [PLWHIV] get angry when I tell them that I want another baby. People have so little information. (Nadia)

When you learn that you have HIV, you realize that you may die not in a month but tomorrow, and it is scary. (Olga)

For them [people who are not living with HIV] HIV is a horrible disease, like death to them. I think 19 people out of 20 would tell you exactly that. (Peter)

For some, [PLWHIV] are seriously ill people with a death sentence. (Constantine)

The data implies that the perspective that HIV is a death sentence is held by both the general public and by PLWHIV before they learn of or are willing to accept ART. Many of the participants expressed that when they were first learned of HIV, they thought that they themselves would have little time to live, and that there would be no future for them. During my interview with Victor, he told me that while he was in prison, in the mid 2000s, he saw people try to commit suicide upon learning of their HIV status because they thought they had no future.

### ***Fear of HIV.***

During the interviews, the participants expressed what the people of Ida-Virumaa are very afraid of: HIV, contracting HIV, and people living with HIV. With the misunderstandings of HIV and the association of HIV with death, it should not be surprising that HIV is feared, yet the fear of HIV impacts the lives of PLWHIV. The participants expressed that they encounter a sense of being feared and fear-related behaviours regularly in their day-to-day lives.

They dash away from us, not only in Narva. Even when they carry out the [community HIV testing], a lot of people first look into the tent and when they learn it was HIV [testing] being carried out there, they say they are in the wrong place. I think that maybe people are scared of [HIV testing], they are afraid that HIV would come to their families. They are afraid to get infected themselves...I think that this is merely a fear that this will happen to them or to their relatives. (Olga)

In additions to the fears of HIV held by the general public, the participants also shared substantial number of stories and examples of how healthcare providers expressed a fear of infection in their behaviours with PLWHIV. Natasha provided a pair of excellent



descriptions of her experience with healthcare providers' behaviour with PLWHIV.

When I first asked her why family doctors fear infection, she said,

It is the usual human fear. Family doctors usually work with papers. [My family doctor] only admits patients on a non-contact distance and he is not an ER worker or an emergency medical officer who is risking his life and his health...Family doctors only fill out papers and talk to you at a desk at a distance. To them your HIV or AIDS does not matter. They do not need this. They do not want the risk of getting infected. The same for a physical therapist, to whom [PLWHIV] go for exercise...they do not face it and do not want to. Human fear and ignorance.

She then followed up this example of fear behaviour, with another behaviour of family doctors in Ida-Virumaa, which she described as being very common.

There are cases when family doctors will not even let an HIV positive into their cabinets. They ask, "what is wrong" from the doorway. There are lots of such stories, and we [PLWHIV] understand them perfectly because they are afraid for themselves, for their families, and for their children.

The majority of the semi-structured interview participants shared similar stories and experiences about how healthcare providers' professionalism was influenced by fear.

When I asked Marianna how she discussed HIV with her friends who are also living with HIV, she said, "We discuss doctors' attitudes. How they take you to the maternity house<sup>21</sup>, the attitude of the [paramedics]. Everybody asks if you have a disease [or HIV] as though they are interrogating you." Nadia shared a troubling story when I asked her why she is afraid to disclose her status to her colleagues who are nurses and doctors, "There is a fear that they will turn away from me or try to kick me out of the team because they do not want such a person there. Of course there is fear but I hope people are [kinder] there."

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<sup>21</sup> The term maternity house refers to small hospitals and clinics that specialize in providing medical services for expecting mothers and are where babies are delivered.

In addition to the fear of contracting HIV, the data point to the possible presence of a fear of being tested for HIV. As part of their duties, Natasha and Nadia both travel throughout Ida-Virumaa to run rapid HIV testing events at social-housing dormitories and venues in the general public. However, as expressed through sharing experiences, it is evident that the general public of Ida-Virumaa seems to be very reluctant or perhaps even fearful of being tested for HIV. Frustrated with this situation, Nadia shared,

Even though I am a [nurse], this fear is responsible for a lot of things. I do not know how to [tell] people not to be afraid, [and] to come and get tested. Out of 20 people, only 5 will come voluntarily. We have to look for the other 15. A lot of people come because we promise gifts to them. [But] there is no understanding that they have to come back and check [the results].

During my stay in Ida-Virumaa, I participated in many such express testing events that were held by the EHPV. One of these events, held in Kohtla-Järve's largest shopping centre on International Tuberculosis Day, really highlighted how much the EHPV staff and volunteers struggled to recruit people to stop for five minutes to take a test. In the first 90 minutes of the event, I counted only five people who took that test, and three of them were already associated with the EHPV. Most of the individuals approached by the volunteers either rudely shrugged them away, or when told about the testing, abruptly said "thank you" and walked away. Although both Natasha and Nadia expressed frustration at individuals' fear of testing, not enough data was collected to clarify the reasons for this general apprehension. Unfortunately, I was not able to stay for the entire event, but when I spoke with EHPV staff the next day, they told me that there were very few people who got tested. Nevertheless, a fear of being tested for HIV merits further investigation.

### *Apathy towards HIV.*

The final subtheme related to perceptions of HIV is that the people of Ida-Virumaa are not interested in HIV and PLWHIV, and are potentially apathetic<sup>22</sup> towards the HIV epidemic. Excerpts of individuals not caring about HIV were not as prevalent as fear of infection or misunderstandings of HIV, yet there was a general consensus that unless an individual is directly affected by HIV, he or she will not be interested in learning about HIV or learning about ART.

[They don't understand HIV], but the thing is that [people not living with HIV] do not want to know. They do not want to know you cannot get infected with HIV through a handshake. (Olga)

Until a person has come across this problem, he or she is not interested. Until I encountered it, I was not interested either. I was not interested in the statistics. I was not interested in whether there was a cure. As soon as people encounter it, they start asking for details. (Nadia)

I think that they are already used to it. So many people have been sick with HIV throughout the years that it has become a norm for them. I think so because we have so many [PLWHIV] in Narva that there is no surprise here that a person has HIV. (Svetlana)

Nadia's statement, "Until a person has come across this problem, he is not interested," was a common theme throughout the semi-structured and unstructured interviews. It implies that unless an individual in Ida-Virumaa has a direct contact with HIV either through personal or professional relations or situations, he or she will have little incentive to learn or search for more accurate information about HIV, AIDS and the HIV epidemic in Ida-Virumaa.

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<sup>22</sup> Public Apathy towards disease, illness, HIV and PLWHIV is not a phenomenon unique to Estonia, as most people and societies have a sense of apathy to conditions that do not directly affect them. However, the sense of apathy towards HIV and PLWHIV in Ida-Virumaa is of particular interest because Ida-Virumaa has been the centre of Estonia's HIV epidemic for the past 16 years.

Daria and Anastasia also shared very interesting descriptions of this sense of apathy towards HIV held by the people of Ida-Virumaa.

“Before I started working at [location confidential], I had very little information about HIV infection. I actually thought that if I got pricked with a needle that was lying around for a while, I would get infected with HIV. I was not informed enough. I studied at two universities but I knew very little about HIV and they had told us very little about it. I did not have any friends who were HIV positive. I never had such friends and that is why I knew very little about this disease.

(Daria)

The majority’s perspective is as the Russian proverb, “it’s no concern of mine<sup>23</sup>”. “If only it would not concern me”. And the attitude is the same, “God forbid it happens to me.” “It is so scary, you cannot live with it.” I think [these thoughts] comes from ignorance. A lot of people are incompetents and uneducated in terms of HIV. They do not understand what kind of disease it is, or that it could be treated. But they are afraid of learning this information because there is a denial of this disease among the majority of the population who do not have a medical background. (Anastasia)

Both Anastasia’s and Daria’s statements support the apathy the people of Ida-Virumaa have towards HIV and that unless a person is directly impacted by HIV, he or she will not be interested in learning about HIV. Anastasia also mentioned that there is a public denial about HIV in Ida-Virumaa. Even though the perspective that “the public is in denial about HIV” was not mentioned by any of the other participants, Anastasia has been working as a healthcare provider in Ida-Virumaa for many years, and her opinion about this sense of denial should be taken seriously. Unfortunately, this study was unable to explore this perspective further, but it will be of interest for future research.

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<sup>23</sup> The phrase, “It is no concern of mine,” (это не мои проблемы/*eto ne moi problemie*) is a very common cultural perspective held by Russians, particularly those who grew up during the Soviet Union. It has been and is used by people to distance themselves from thoughts or issues that are viewed to go against the shared cultural or ideological norms of the population or the state.

### **HIV Stigma: Perspectives of People Living with HIV.**

The theme Perspectives of People Living with HIV examines how the participants felt the general public perceived PLWHIV and consisted of four sub-themes: (1) *Spidoznii is Narkoman*, (2) PLWHIV are less than human, (3) PLWHIV are not worthy to be in society, and (4) *sam vinovat*. This section uses various excerpts from that data to support and provide a context while each subtheme is explored. Some of the excerpts of texts are presented in both English and Russian to identify language use of the cultural metaphors used by the participants.

#### ***Spidoznii is Narkoman***

The first of these subthemes, *Spidoznii is Narkoman* (Спидозный значить Наркоман), details how the participants felt that the general public of Ida-Virumaa, and perhaps Estonia as a whole, associate being HIV positive with being a drug user, specifically *Narkoman*. *Narkoman* is a Russian word used to describe a person who heavily uses drugs, primarily intravenous drugs, and struggles with addiction. *Narkoman* is also a very negative word charged with symbolic meanings and negative stereotypes. Unlike the more politically correct or sensitive term *zavisimei chelovek* (зависимей человек) which is used to describe a person struggling with addiction, *Narkoman* translates as a negative word for addict or drug-user, but it is closer in meaning to the term “junkie”.

People who have not had experiences with drugs treat *Narkomani* (plural) as filth (гряз *gryaz*) and not a person (не людям *ne lyudyam*). (Victor)

*Narkoman* [is a person] who has a life of chaos, who lives amorally. A person who is low status (ниже статуса *nije statusa*). (Constantine)

If you are a drug addict in Estonia, they treat you with prejudice; you are not a human anymore. There is also a saying that there are no former drug addicts. If you are a drug addict, you have it for life. No one believes that you quit and stopped taking. (Peter)

Although these participants did not use it, the meanings they express are synonyms with the word *Spidoznii*. The word *spidoznii* (спидозный) is a very negative slur used to describe people who live with HIV. Literally translated, it means AIDS-man (*spidoznii* спидозный) or AIDS-woman (*spidoznaya* спидозная). Due to the popular impressions that there is no difference between HIV and AIDS, the slur is used to describe anyone who has or is suspected of having HIV.

Unlike other phrases to describe a person living with HIV such as *Vich Positivni* (ВИЧ Позитивный, HIV-Positive), *chelovek kotorii zhiveot s Vichom* (Человек Которы живет с ВИЧ-ом) or *Vichevuikh* (ВИЧевых, person with HIV), *Spidoznii* is a very negative word and was never used by any of the participants to describe themselves or other PLWHIV.

There is a general opinion that HIV is AIDS. And in ordinary conversation HIV positives are called *spidoznii* and it does not matter that these are different things. People know theoretically, but when it comes to attacking and negative sayings, it's all generalized into one pile and a person is called a *spidoznii*. So there is information, but the reaction is different. It is aggressive. (Natasha)

We have a group of people, *babushki*<sup>24</sup> (old ladies) we call them. They sit on a bench and with reason or for no reason they suspect that a person is a drug addict

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<sup>24</sup> *Babushki* (plural form of *babushka*) are elderly ladies that have retired and are living on pensions. In Russian cities, including Narva and Kohtla-Järve, it is very common to see either individual or groups of *babushki* sitting on city benches, which are located in front of each apartment building, talking to each other, gossiping, and watching people on the street. They are very observant of the comings and goings of members of the younger generations and they share their observations within their circles. If a *babushka* witnessed a person she knew entering either a known HIV clinic or a methadone centre, she would openly share her observations with her circle and soon many in the town or city would know that that person went there. In a way, *babushki* act as the sentinels of morality in Russian society, and many of the participants

or they know that a person is *narkoman*. They say, “There goes *spidoznii*.”  
(Nadia)

The term *spidoznii* is important because it helps emphasize the synonymous meaning between a PLWHIV and *narkoman*.

Seven out of the eight semi-structured interview participants strongly felt that the general population of Ida-Virumaa saw no differences between PLWHIV and IDUs, to the point that the terms may be interchangeable.

HIV means prostitutes, drug addicts, drugs, filth – those are the associations  
ВИЧ это проститутки, наркоманы, наркотики, грязь - вот такие ассоциации.  
(Marianna)

They lump everyone together. If you have HIV, it means you're a drug addict, anti-social, a finished person.  
А косят всех под одну гребенку. Если вы больны ВИЧ, значит вы наркоман, антисоциальный, конченный человек.  
(Victor)

The attitude was the following: you are a drug addict and a HIV positive, or vice-versa. In general, one made another worse.  
Отношение поэтому было такое: ты наркоманка, да ещё и ВИЧ позитивная, или наоборот. В общем одно усугубляло другое.  
(Olga)

These shared perspectives imply the presence of a common belief that links the status of being HIV positive with the status of using drugs and negative symbolic meaning associated with *Narkoman* is also applied to a person living with HIV. What is particularly interesting is that association between *Narkoman* and *Spidoznii* applies to individuals regardless of how they acquired HIV. When I asked Victor if the people who are not HIV-positive saw a difference between a person who contracted HIV from drug-use and a person who contracted HIV from sexual intercourse or from another means, he

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were very concerned and cautious around *babushki*, and afraid about what rumours might be spread about them.

bluntly replied, “There is no difference!” On reflecting her experience, Valentina provided a further explanation to Victor’s statement.

I think out society still thinks that PLWHIV are only drug addicts. People think that HIV is a drug addict’s disease. But at my work I have understood that HIV is a regular person’s disease. A person who may have cheated on his or her spouse somewhere a long time ago. Or maybe it was when they were young. So they have been infected through sexual intercourse...Society has not realized that there may be HIV-positive people among the regular, working, [non-drug using] positive population. There are a lot of such people. And recently there have been more new [HIV] cases in regular people than drug addicts.

The symbolic inseparability between an HIV positive status and drug-user status seems to be well entrenched in a cultural belief that it is even held by some healthcare providers.

Natasha shared an experience of one of her clients, who was HIV but had no history of intravenous drug use,

Many HIV-positives get adapted to a situation and go for a treatment to other towns, for example, in Tartu. It is somewhere, where no one knows them, where a doctor would talk to them normally and will help. Somewhere no one would blame or reproach them, if something happens to his or her health. Not like how it is happening here (Ida-Virumaa). Our doctors have driven a woman to two [psychological breakdowns]. She was taking Treatment Scheme I<sup>25</sup>, which was unsuitable to her. But the doctor blamed her and accused her of not taking the therapy. The woman tried to explain that she had not lied, that she was not an addict and that she had two adult children, but the doctor did not believe her and insisted that the tests showed that the woman did not take her treatment. The woman was driven to such a state that she had to be taken urgently to Tartu. She stayed there for 6 months until she stabilized, learned how to walk again and recovered. They [the doctors in Ida-Virumaa] destroyed her with distrust. (Natasha)

The symbolic association between an HIV positive status and being a drug-user was also held by some of the participants in the past and may still be viewed as the same by PLWHIV in Ida-Virumaa.

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<sup>25</sup> Treatment Scheme I refers to a preset combination of antiretroviral medications provided by *infectionists* to PLWHIV in Estonia.



Natasha also shared a very emotional story with me about how she unintentionally infected her one of her past boyfriends with HIV because she had assumed that he was already HIV positive, as he was also a drug user.

I was in a relationship with a guy and I was sure that he knew or that at least he would ask [about my status]. But he did not and I thought that he also had HIV. The result: it turned out that he was not HIV positive when we started dating, but then he fell sick. And I did not know: have I infected him or has he been infected somewhere else? When we broke up, it became clear that he had been infected as well. We tried talking, but he thought it was all my fault. And actually I told him, but it was too late. Yes, I lied to him for some time, but not because I wanted to, but because he asked when it was too late. And when I realized that he did not have HIV, we had already been having sex without condoms and we had shared the same syringes. I had such bad veins that I always took a new needle, and he used it after me. And when I learned that he did not have HIV, it was too late. He was convinced that I did not have HIV and I was convinced that he had HIV. (Natasha)

Understanding the powerful symbolic association between *Narkoman* and *Spidoznii* is important when examining the other subthemes related to perspectives of PLWHIV, for the perspectives and meanings applied to IDUs are also applied to PLWHIV and vice-versa. Moreover, it seems that the overall perspective of the general public is that while not all IDUs may have HIV, all PLWHIV are either IDUs or prostitutes and that HIV comes from drug-use. However, these cultural perspectives of HIV as a disease of intravenous drug-use are not only very problematic, but also no longer reflects the reality of Estonia's HIV epidemic. Although between 2000 and 2014 HIV prevalence was highest among intravenous drug using demographic, 2015 was the first year where the number of new HIV case in the general population was greater than the number of new HIV cases among the IDU, CSW and MSM populations. In 2015, two-thirds of all newly identified HIV cases were among individuals who neither had a history of intravenous drug use, nor belonged to an at-risk population (BNS, 2016).

### ***PLWHIV are Less than Human.***

The second subtheme related to perspectives is that PLWHIV are seen as being less than human. This subtheme emerged from the data with powerful expressions and metaphors as many of participants clearly indicated that they felt the general public viewed them as being less than human. Phrases that were commonly used by the participants included the following: you are no longer a person (ты уже не человек, *ti uzhe ne chelovek*), a finished person (конченный человек *konchyonnii chelovek*), being second grade (второй *сорт* *vtoroi sort*), and lower status (нижней статуса *nizhnei statusa*).

If you are an HIV-positive person then you are a second grade<sup>26</sup>. But what am I saying, what second? You are not a person anymore.  
(Victor)

If you are a drug addict in Estonia, they treat you with prejudice; you are not a human anymore. There is also a saying that there are no former drug addicts. If you are a drug addict, you have it for life. No one will believe that you have quit and stopped using.  
(Peter)

These perspectives of been seeing as less than human have very negatively impacted the lives of PLWHIV and help to foster a sense of internal stigma that may place substantial social limits on a PLWHIV. Describing how internal stigma influences a PLWHIV in Ida-Virumaa, Daria stated,

Men and women see themselves differently. For example, [young women] are very worried that they will not be able to find a [partner or spouse]. Young women [living with HIV] see themselves as having less value. That is their main

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<sup>26</sup> Second grade (второй град/vtoruii grad) is a Russian term used to describe a person who is seen to be lesser than oneself. The term does not necessarily mean that an individual is a second-class citizen, but means that a certain individual is beneath another and is not worthy of being included into a particular social group. In essence, if an individual is marked as being second grade, he or she is ostracized from that particular group. In the case of Victor, he is implying that he and other PLWHIV are ostracized from all social groups that learn about their status.

problem. They even wanted to create a website where girls and guys with HIV could meet... They think that as soon as their partner learns about their status, she will be dumped or divorced. Guys have it simpler, and they just do not care about anything. But there are guys who are not addicted [to drugs] and they are also very worried. There are a lot of PLWHIV who are afraid of publicity and are willing to go to another town [for treatment]. And they fear that others will not accept them. They just do not see themselves as being full-value.

Daria's description about how young women living with HIV feel that they are half value is very important in understanding the internalized stigma of Russians living with HIV.

Unlike contemporary western cultures, Russian culture has very strongly defined gender roles and expectations for men and women. During experiences living in Russia ten years ago, I learned that Russian women are expected to be as beautiful as possible whenever they are out of the house, and that they will not find a partner if they are not. There is also the social expectation that Russian women are to marry young, (late teens and early twenties) and to start having children as soon as possible, and that if a women reaches the age of 27 or older, she is not seen as having value and is likely to earn less than a married woman. Although these cultural perspectives have loosened a little over the past ten years, women are still pressured to marry early, and women living with HIV feels that their status may prevent them from finding a partner who would accept them, and that they may be ostracized not only for being HIV positive but for not being married and not having children.

In addition to the comparison of PLWHIV to that of less than human, some of the participants felt that the general population saw PLWHIV like lepers (прокажено *prokajheno*). Despite the reference to people who suffer from leprosy, in Russian culture, referring to someone as a leper is a very powerful cultural metaphor to describe him or her as being untouchable, disgusting, and less than human. The fact that the participants

used this metaphor to describe how the people of their communities see them demonstrates how poorly they feel others view them. During our interview, Peter told me, “the majority is far from [accepting] and they treat [PLWHIV] as lepers. For them HIV is horrible disease, like death to them... But the majority is ignorant and they see us as lepers.” Using the cultural metaphor as being equal to a leper highlights the feelings of being seen as less than human. The metaphor of being a leper combined with the overall feelings of being less than human not only highlights some possible difficulty of a PLWHIV living in the community, but it also helps in understanding how the general public feels about PLWHIV.

The powerful symbolic metaphor of being less than human emanating from the perspective that PLWHIV are less than human was deeply felt by many of the participants. As mentioned in the previous section, the strong cultural perspective of HIV being a disease of intravenous drug users suggests that regardless of how a person contracted HIV, they are also less than human. The feelings of being seen as less than human troubled many of the participants, and many of them, particularly the female participants, felt one of the things that needed to change regarding HIV in Ida-Virumaa is how people see PLWHIV. Mariana clearly demonstrated these feelings of frustration, “The most important [thing] is that people need to understand that regardless of whether a person is sick or not, he is still a person. ...People need to know that people with HIV are also people, not mutants.” Within her statement, Marianna identified a plea that was echoed by the majority of the other participants, “People need to know that those with HIV are also people”. During each interview, I asked the participants what they thought people who were not HIV positive needed to know about HIV, and the most common

answer was that “PLWHIV are people too”. The distribution of this feeling across the semi-structured and unstructured interviews implies that the feeling of being subhuman impacts the lives of PLWHIV and it is something they strongly desire to change.

***PLWHIV are Not Worthy of Society and Should be Avoided.***

The combined subthemes of *Spidoznii* is *Narkoman* and PLWHIV are less than human provide a framework for understanding the next subtheme that emerged from the data, which is that PLWHIV (IDUs) are unwanted and unworthy in society and that one should not associate with them. The perspective of not being wanted or of being unworthy of society was held by many of the participants:

[They see that PLWHIV] are contagious and they have to be taken to a deserted island, have a brand put on their forehead, so that everyone can see. They cannot be hired or cured, and they cannot do anything. [They should] just stand aside... they should be isolated, kicked out, deleted and that is all. (Natasha)

Even though there have been many talks about it, people are still not ready to accept HIV-positives as full-plledged members of society. They think that such people have to be isolated from those people who do not have HIV. They can exist but somewhere separately from others. (Olga)

After that [my friend] said, “I would never offer my hand to an HIV-positive” (Marianna)

Although all the participants did not share the perspective that PLWHIV should not be allowed to participate in or are unworthy of society, many of the participants shared that they are very afraid of being socially excluded, not only from public day-to-day life but from family and friends as well, if news of their HIV status was disclosed. At the beginning of the chapter, Olga shared her past fears of being excluded from her family if they had learned of her HIV status, and she continues to fear that if her mother-in-law learned of her and her husband’s status, they would become outcasts.

Daria provided an excellent explanation of how the perspective of not being worthy influences the life of a PLWHIV in Ida-Virumaa.

Society does not accept them because society behaves in such a way. [They] talk and think about PLWHIV very badly. And a [person living with HIV] shuts down and is afraid of saying that he has HIV because society will not accept him and will not understand. So an internal fear is created, an internal stigma that they will be discredited because he is a drug addict and has promiscuous sex. Society does not accept [HIV]. It does not treat it as tolerantly as it should. (Daria)

The perspective that PLWHIV are unworthy of society, however, is not only an internal stigma, but also reflects a common perspective held by the general public towards PLWHIV. Marianna shared a statement that one of her friends had prior to learning her own HIV status, “[Before I learned about my own HIV positive status], I would never have offered my hand [in marriage] to an HIV positive.” Even though Marianna’s friend changed her perspective after learning that she too was living with HIV, this ideology highlights the notion that PLWHIV should not be associated with.

The learning of an individual’s status can also cause that individual’s friends and family to change their perspective of him or her.

There is a person with whom they have been familiar for a long time. And then they learned that their friend had HIV, so he was not worthy of a handshake. (Olga)

They are afraid of [PLWHIV] and avoid [us]. You invited me to have some tea with you, but others will not invite me for tea. They fear being infected, so it’s better if they do not know. (Victor)

Despite the fear of contracting HIV, both of these statements also express a deep cultural insight into how the general public believes that PLWHIV need to be avoided. As briefly mentioned in the previous chapter, handshakes and having tea with someone is

very important in Russian culture and refusing either a handshake or to offer tea to someone carries very strong views of how you see that individual.

The handshake is a mandatory cultural greeting among Russian men and is exchanged at nearly all meetings between friends and acquaintances. It is used in a similar fashion, as a person would say “Hello. How are you?” in Canada. While living in Russia, and in Ida-Virumaa, I often saw Russian men go meters out of their way, including crossing a hall or a street, to shake the hand of someone they knew before moving on their way, and I quickly learned that I had to shake the hand of every man I ever met every time I encountered him. The handshake represents not only a means of greeting but also a symbol of camaraderie and respect for that individual. Therefore, a man refusing to offer or shake another man’s hand sends a strong message to how he views that individual. By refusing to receive a handshake or by not offering one, a man is essentially saying that he does not consider the other man to be a part of his circle and that he does not deserve respect. Such an act is a sign of public exclusion of the individual and is very demeaning and insulting. The Canadian equivalent would be refusing to say “hello” to someone you knew after you made eye contact. Returning to Olga’s statement about her friend, the fact that the individual’s former friends would refuse to shake his hand identifies not only a poor knowledge of HIV etiology, but also how they saw this him as being unworthy of their respect. Although it would be premature to conclude that the denial of a handshakes is a result of seeing a person as being unworthy and not just out of fear of contracting HIV, it is still very insulting to a PLWHIV and may leave a man with a sense of either not being wanted or being less than human.

Tea culture in Russia is very different than contemporary tea and coffee culture in Canada as the emphasis is on social interaction and maintaining social relationships between individuals. When a person invites you for tea, it is important to understand that this will not be a half-hour or hour visit, but that the entire tea experience could last multiple hours, as the tea invitation can quickly become an invitation for lunch, then to dinner, and then for vodka in the same evening.

As a social experience, Russian tea-culture is closely tied to hospitality, an important aspect of the Russian soul. Bouchard (2003) described the Russian soul as an important aspect of Russian national identity and a positive portrayal of the Russian national character. He describes the Russian soul by emphasizing the perspectives that Russians are kind and peace-loving people while at the same time distinguishing the Russian identity from negative, or deviant, traits of laziness, drunkenness, and frivolity (Bouchard, 2003, p. 236). He also explains that hospitality is a central trait of the Russian soul, and Russian hospitality is used to distinguish Russians from other nations or ethnic groups in Estonia (Bouchard, 2003, p. 239). As Russians identify themselves as being the most hospitable, it is important for Russians to invite others into their homes for tea, lunch, dinner or a night of drinking or games. As sharing one's hospitality is an important aspect of Russian identity, not inviting an acquaintance for tea, either at home or outside of the home, tells that individual that he or she is not worthy to be associated with, and acts as a way to enforce metaphors of what is acceptable and deviant behaviour.

In addition to the sense the PLWHIV are unworthy of society, there was a common ideology shared that PLWHIV should be avoided. Despite the high prevalence of HIV in Narva and Ida-Virumaa and the shared feelings that HIV, particularly in Narva,



has affected large portions of families, it was commonly reported by the participants that PLWHIV should not be associated with. To express this, the semi-structured participants used an interesting cultural metaphor to describe how people avoided them, “they run from us like the plague”. Comparing HIV and PLWHIV to the bubonic plague (чума *chuma*) and plague victims is a very powerful cultural metaphor and was used frequently by Victor, Olga, Natasha and Peter to describe both the fear of HIV and the strong desire to avoid PLWHIV in Ida-Virumaa. Victor shared a particularly dark story of how people saw HIV and PLWHIV while he was in prison during the early 2000s,

I will tell that earlier, when people knew very little about HIV, particularly those who had spent a lot of time in jail, HIV-positive cellmates were avoided like the plague [как чума]. There had been stabbings and that's why people with HIV had to have their own block.

### ***Sam Vinovat***

The final subtheme of perspectives of people who live with HIV was the notion that a person who has contracted HIV is solely responsible for their HIV-positive status, and that it is his or her own fault (сам виноват *sam vinovat*). Although not all of the participants expressed this perspective in the interviews, the perspective that it is a person's own fault if they have contracted HIV was prevalent enough in the data to suggest that this is a commonly held perspective towards PLWHIV.

In general, they, [the general public,] think that [PLWHIV] are all drug addicts or prostitutes because the majority thinks that it is their own fault that they got infected and [that] they should have thought with their heads. (Nadia)

They mean that – if you have HIV, it is your fault. Here in Ida-Virumaa people see it this way – if you are a drug addict, you must have HIV, no other way. (Natasha)

The notion of *Sam Vinovat* is related to the cultural association of HIV being a disease of drug-users. This implies that if one has HIV, he or she must be a drug user and that if someone does not have HIV, then the person is not an intravenous drug user. Even though the perspective that a person living with HIV has only himself or herself to blame for having HIV, not enough data were collected to inference that there is a sense that HIV is a punishment for poor or amoral life choices. Though the other subthemes imply that HIV may be seen as a punishment, it will need to be investigated in future research.

***Additional Characteristic of HIV Stigma: An Epidemic of a Generation.***

In addition to the previous theme cluster of *HIV Stigma*, analysis of the data highlighted another very important characteristic of HIV stigma in Ida-Virumaa. As HIV incidence and prevalence in Ida-Virumaa is almost explicitly associated with the 25 years old and older demographic groups, the production and reinforcing of HIV stigma also seems to be associated within this demographic.

The [recent change in the] epidemic stems from unawareness in the field of safe sex. Second, open relationships. This epidemic was caused by it. And it can be rather big because these people hold very big stigma. Young people keep it much simpler. But the generations of the [1950's to the 1970's] hold very large stigmas [towards PLWHIV]. It is much simpler with young people under the age of 25 because, thanks to Estonia's policies, students know everything [about HIV]. I doubt that the policies are the same in Russia... The epidemic is not among young people. It is in the older generations. (Anastasia)

I [am very happy] that young people are not afraid of HIV. Elderly people and people older than 30 are very afraid of HIV. But young people are not afraid. They do not care if someone has HIV or not. But they are not infected [with HIV], by the way. They do not fall into the [at-risk] groups. We test teenagers quite often and if it is a normal, studying teenager from a normal family, not a hobo<sup>27</sup>

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<sup>27</sup> The term hobo (асоциал/*asotsial*) is a Russian term used to describe homeless people. In Ida-Virumaa, this term is used primarily to describe people living in social housing, which are old dormitories. The individuals living in social housing usually struggle with addiction and/or mental illness, and usually suffer from multiple serious health conditions including HIV, hepatitis, and tuberculosis. Although Anastasia used the term асоциал/*asotsial* to refer to "hobos", it is a very polite word to describe those who are homeless and unemployed compared to the more commonly used Russian words to describe the homeless.

*narkoman* or alcoholic, he or she is not at risk. They always easily come to testing and they are more communicative. They are not afraid of HIV. They have heard about it a lot...you might even say that they [and HIV] grew up together. (Natasha)

Doctors and nurses who were trained in the USSR treat us negatively. Young doctors and nurses treat [HIV] differently. I suppose they know more about it. They treat us like we are regular people. They know that you cannot get infected with HIV through a pen or a mug. Maybe they want to know, to learn more about it for themselves. Those who are older do not want to; they think [that they already know enough]. (Olga)

This association of HIV stigma being primarily held by the older generation and by doctors who were trained during the Soviet Union was commonly encountered during participant observation. During some lunch meetings, EHPV staff and volunteers often told me about how HIV stigma is only held by people of the Soviet generations who never learned about HIV. The EHPV staff and volunteers also identified that the doctors who were the most discriminating towards PLWHIV were trained during the Soviet Union and are approaching retirement age.

### **Barriers to Care: Fear of Disclosure**

The stigma associated with HIV and PLWHIV in Ida-Virumaa not only limits the opportunities and daily life of a person living with HIV but also influences his or her care-seeking behaviour. The powerful negative cultural metaphors associated with PLWHIV and HIV have resulted in many people living with HIV being very cautious and afraid of having their HIV-positive status disclosed and the potential negative social consequences that may result. Both Olga's story and examples in the previous section identified the strong unwillingness of the participants to share their HIV status with others. Although there are some PLWHIV in Ida-Virumaa, like Natasha, who are very open and confident about their status, they represent the minority, as most of the

participants felt that the disclosure of their status would have negative consequences for them and their families.

There is [Natasha]. She urges everyone to be open [about their status] (laughs). I have already explained to her my position, that if my children were at least 18, I would openly share my status. I mean the children are grown up and how others will treat them is not as important. ... People are different and they may have an inadequate reaction. I am also like that. If I had learned that in the kindergarten there was a child from infected parents, I would also have demanded that the child be checked. (Nadia)

I do not want to hang a sign on myself that says I am sick because [people] will write you off immediately. They will ridicule you and they can make even the strongest person kill himself with their words and disregard. [They] can break a person with a strong spirit, even one who knows that life goes on [with HIV]. You just have to move on and if you have someone to live for, you consider yourself useful in this society. Those who will not understand should not be told. You can break anyone. This is why I am not saying and not sharing [my HIV status]. It is mine. (Victor)

Participants were also concerned that the disclosure of status could result in loss of employment.

[People] are afraid of working [because] what if everyone learned that they had HIV? ...There are no laws with which people can fire you because you have HIV, but they will find another reason [to fire you]. Or they will ask you to quit voluntarily, or they will find another excuse to fire you. (Natasha)

I am afraid that [if my colleagues learn about my status,] they will turn away from me or try to kick me off the team because they do not want such a person there. (Nadia)

After I worked in the mine, my old coworkers told my new employer that I was a drug addict, and [I lost my job]. I do not know why they said that, as I was already a normal person [and had stopped using drugs]. (Peter)

The participants who also had children were very concerned about others learning of their status because they feared that the stigma associated with having HIV would also be ascribed to their children. More specifically, they were worried that if other parents and teachers learned about their status, their child would become an outcast, as other

parents would tell their children not to socialize with the child of a person living with HIV. They were also concerned that other parents may force their child to be tested and share the results, or simply remove their child from kindergarten or school.

One of my children went to kindergarten with a kid whose grandmother used to work as a nurse at the town hospital. I did not want to encounter her. I do not know whether or not she said anything, but I know for sure that she understood why I was [at the hospital]. Such a negative experience... and it is only because it accompanies the identification of the [HIV] status... It was unpleasant, but health is more important. Of course I got the [baby] formula and the consultation, but that grandmother had already known. I still greet her in town, but she knows everything about me. I do not know how long her tongue is or if she told her children. I do not know that. (Marianna)

[My children] are the only thing that I am worried about. I am not worried about me, honestly, but for my children and for my family. I can always stand up for myself and answer [others], to sit down and [discuss] HIV with them. I can explain it to even the stupidest of people. But I do not want my children to suffer because of [my HIV], and I [should not] always have to prove that they are healthy (Victor).

My eldest child is almost 10. He is already all grown up. He does not know that his parents are HIV-positives. I do not want him to find out, and I cannot imagine how I would tell him. I guess that he should not be told. (Olga).

This implies the perspective that the cultural metaphors of HIV and HIV stigma associated with PLWHIV can also be inherited or transferred through association with a person living with HIV.

This is particularly problematic for a person living with HIV in Ida-Virumaa because, unlike in Canadian society, publicly chastising someone for deviant behaviours or beliefs is acceptable in Russian culture, particularly by members of a social collective<sup>28</sup>. For people living with HIV, social collectives represent a serious

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<sup>28</sup> Social collectives (коллектив *kollektiv*) are influential social networks formed by groups of people in a similar demographic/profession, such as housewives, *babushki*, teenagers and young mothers, in a specific neighborhood or workplace. Social collectives represent micro-social hierarchies that are limited to their location, either an apartment building, or group of apartment buildings, or a workplace, and are very important, influential and powerful as they control or regulate social behaviour, deviance and an

complication in their day-to-day life because if a member of a social collective learns about his or her status, it is very possible and probable that the knowledge of the individual's status will be quickly spread throughout the community. This, in turn, provides individuals of a social collective(s) or aspiring members of a collective a social license to publicly chastise a person living with HIV. The chastising can take many forms from the spreading of rumors, to losing one's job, to bullying, to being forced to move, exclusion from collective and social events, verbal and emotional abuse, or, in extreme situations, physical abuse.

During one of my trips to Tallinn, I met with Dr. Kristii Rüütel, who is a senior researcher at Estonia's National Institute of Health Development. She shared with me a particularly disturbing story about physical abuse related to HIV. According to her, there was an incident a few years ago, where a child was stoned by classmates in the school playground. Although she was unable to provide me with more specific details, the child was stoned because the classmates had learned that the child's parents were HIV positive. Unfortunately, Dr. Rüütel told me that, although this represented an extreme case, verbal, emotional and physical violence towards people living with HIV and children of people living with HIV is not uncommon, which only encourages PLWHIV to hide their status from friends, acquaintances, and family.

The fear of having others learn of their HIV status not only impacts the daily lives of the participants but also makes accessing care very difficult for them, particularly if

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individual's status within that community. For many Russians, it is very important to either belong to one of these groups or at least be in positive standing with the collectives because it usually results in having a positive relationship with your neighbours. Unfortunately, having a poor relationship with one or more of these collectives can result in serious negative social, economic, and psychological consequences for an individual, particularly if that individual is seen being socially deviant.

they fear that someone can identify them while they access care or if healthcare professionals will share their status with others in the community.

Once, I had an experience at the town hospital, when I went to see the *infectionist*. The entrance was for everyone, from where you could get pills and baby formula. At the entrance to the hospital, the nurse who gives out the pills [ART] and formula was frequently absent, and I had to ring the common bell to call her. There were a lot of medical staff and nurses who knew me. If I am going to that office [in the hospital], it means that something is wrong with me. They must have thought that. If I show up there twice a month, then I must have such problems. Such behaviour sheds light on [someone's] status and points at my problems. I was not comfortable in this situation. (Marianna)

There are people [like me] who are not afraid of their status and are living openly with it, but most people who live with HIV are trying to run to the hospital secretly, so no one will see them. God forbid if someone sees. I have a client. She was scared to take a fluorography because she knew that her friend worked in the X-Ray department. She understood that if she went there, everyone would learn about her status. But her daughter got pregnant and she had to have an X-Ray [to detect] medical conditions because she wanted to partake in her daughter's labor. And her [HIV] status was revealed. (Natasha)

There is a story about a confidentiality breach because we have disability documents and they are applied through the pension department. One time an employee [from that department] decided to have revenge on a girl who was HIV positive. She told [the other girls status] to all the neighbours. The documents were sent there and she saw them. I am not a social worker but ...I signed papers that state I do not have the right to disclose [patient information]. Even if I meet someone on the street, it is better if I pretend I do not know him or her. And a social worker goes and tells everyone. (Nadia)

The combination of HIV stigma and fear of disclosure results in the participants being very selective about where they go to receive care and if they go at all. The location and layout of the services sought influence whether or not a participant will access care.

I would prefer [to go for treatment] in a public hospital where there would be a separate entrance [for PLWHIV] and no sign on the door that this is the HIV [patient] cabinet. It should be confidential and only those who need help would know about it. I want to be sure that no one would point his or her fingers at me. A lot of people do not go to the doctor or receive therapy because of that. They are afraid that they can be seen and this information will spread and negatively affect them. (Olga)

I have [never been afraid of others learning my status] because we have a separate hospital here. If we had the same thing in Narva, I would not even go for a check-up...because people will learn [about my status]. I already had difficulties because of that. I believe that some people do not go for checkups only because they are [afraid of] that. They think that they [have HIV], but what will other people think about them? They take other people's opinions very seriously. (Peter)

[Location for services] is a big deal to me. I do not want to go to a place where someone might know me and learn about my status. [Not even] my friends and family. If a person were sitting in the hospital and saw me collecting my box [of ART], I wouldn't like it. I do not want the whole world to know about my status. Confidentiality matters to me. (Marianna)

These testimonies identify that many participants, particularly those in Narva, are unwilling to access care out of fear of being identified as having HIV, and the location and layout of a HIV clinic plays an important factor in their decision to access care or not. Fear of disclosure represents a serious challenge for PLWHIV in Ida-Virumaa. Being identified as having HIV/AIDS can result in very significant social and economic repercussions, yet many participants are placed in a situation when they need to choose between accessing care for HIV, or risk losing their jobs and/or becoming ostracized. Although many participants are willing to navigate these risks to access care, they, unfortunately, face yet another significant barrier to care: healthcare providers themselves.

### **Barriers to Care: Discrimination by Healthcare Providers**

The final theme cluster of barriers to care that emerged from the data indicated that the behaviour and actions of healthcare professionals in Ida-Virumaa also acted as a barrier to care for PLWHIV. The participants shared many stories about how they and people they knew overcame their own internal stigmas and the fear of being identified as having HIV while accessing care, only to experience hostility, outright discrimination,



and unprofessional behaviour from the healthcare providers they saw for treatment. This theme cluster contains five themes of how the behaviour of healthcare professionals acted as a barrier to care for the participants: (1) being talked down to, (2) being refused adequate service, (3) discrimination and unprofessional behaviour from healthcare professionals, (4) a lack of knowledge about HIV, (5) a loss of trust and frustration towards healthcare professionals. Table IV displays the distribution of themes as they emerged in the interview transcripts. For this section the term healthcare providers is used to refer to different professions that provide services to people who live with HIV including doctors (family doctors and *infectionists*), nurses, physiotherapists, and social workers who often work alongside doctors and nurses.

### **Being talked down to.**

The participants identified that they have frequently been talked down to while receiving services from healthcare providers, stating that they and people they knew were often insulted and belittled while visiting a healthcare provider. Expecting and young mothers had even been told that they, their children or their unborn children are or will be undesirable people.

They are even saying it straight. I have an experience. I went to the doctor to get a reference and she asked me directly: “what did you expect with your diagnosis?” And you can kill someone with those words if you say it with a certain intonation. A person can get gutted and decide that he has nothing to live for. (Victor)

[To doctors] this is something outrageous...that drug addicts have children. And they also have HIV. Why would they have babies? During my last pregnancy and labor, when I came to the doctor and told her that I was pregnant and about my status, she told me, “you do understand what kind of baby you will have.” (Olga)

Table IV

Summary of Content Analysis for Discrimination by Healthcare providers as a Barrier to Care

Participant	Subtheme 1 Being Talked down to	Subtheme 2 Refusing to provide Services	Subtheme 3 Discrimination or Unprofessional Behaviour	Subtheme 4 Lack of knowledge about HIV	Subtheme 5 Lack of Faith in Healthcare providers
<i>Semi-structured interviews</i>					
Constantine	X		X	X	X
Marianna	X	X	X	X	X
Nadia	X	X	X	X	X
Natasha	X	X	X	X	X
Olga	X	X	X	X	X
Peter	X		X	X	X
Svetlana	X			X	
Victor	X	X	X	X	X
<i>Unstructured Interviews</i>					
Anastasia	X	X	X	X	
Daria	X	X	X	X	X
Valentina	X		X	X	

The frequency of being talked down to implies that some healthcare providers share a very similar perspective of HIV and PLWHIV that was discussed earlier in the chapter. Participants felt that the doctors saw them as being less than human, and not to be associated with.

This situation poses a significant challenge to efforts to control the HIV epidemic because PLWHIV are less likely to return to receive help from a healthcare provider that openly belittles and/or insults them. While encouraging people to access care and adhere

to ART is one of her duties, Natasha explains that how a healthcare professional talks to a patient influences his or her willingness to return for care.

We are working with drug users in the name of recovery. I personally establish the relationship through the prism of recovery, not by minimizing the damage but to convince a person to quit drugs. And as a rule, such people start recovering. They start establishing their relationship with the doctors. I see how difficult it goes for those with addictions, and a person then starts to have addiction stigma. He understands that he is bad, a doctor sees him as bad, he comes to a doctor and he is always guilty and some people feel guilty but some are angry and do not want to do anything. Why should I go there? So that he would start reprimanding me again? I already know what he has to say to me, what he will do. He will not do anything because I have HIV and they are trying to forecast what the doctors will tell them and what they will do instead of going there to deal with it.  
(Natasha)

Natasha's statement outlines the possible internal conflicts that PLWHIV may face after experiences of being talked down to by a healthcare professional. Considering the negative internal and external stigmas associated with HIV and PLWHIV, it is understandable that a person living with HIV would be hesitant to visit a doctor, especially if that doctor demeans or insults them. Unfortunately, the above situation is a frequent occurrence for Natasha.

### **Refusing to Provide Adequate Care**

In addition to being talked down to while receiving care, the participants shared many experiences of when they accessed care, during which they did not receive adequate care or were even denied care because of their HIV status.

Even when I had my baby, a nurse came. She had to undress a baby and check the umbilical cord but she only asked if we were doing okay. I replied that everything was fine and she left and she did not even touch the baby. She did not check anything; she got scared of a little baby because his mother had HIV. (Marianna)

Whom should I turn to? Where should I go, to my family doctor? My family doctor knows. She shrugs her shoulders. She tells me not to get sick very often. I can say one thing: when I started taking medications I was not that sick. But when I did not take medications, I got sick very frequently. (Victor)

And I hear that from patients... It mainly concerns family doctors who refuse to deal with the patient because there is an *infectionist*. For example, a patient comes with a running nose, he comes with a surgical problem, but he is told that it is HIV's fault. How can a doctor say that without doing an examination and analyses? One can say that a disease comes from HIV when it is the first stage and HIV is only suspected. One can say that when it is the last stage, the AIDS stage. HIV causes a lot of complications, but even in that case a diagnosis must be made. How can a doctor say that a running nose comes from HIV? A doctor does not have the right. But they do so. (Anastasia)

Being denied care or perceiving they are not receiving adequate care was a serious issue for the participants, and one that left them with feelings of anger and resentment towards healthcare providers. Although not all healthcare providers have denied them services, there was a shared feeling that the healthcare providers do not want them and that the services they offer and their intentions may not be genuine.

Natasha shared another story with me about how not providing adequate treatment makes PLWHIV very distrustful of healthcare providers.

I had a case. 2 women stopped taking drugs but their health, general health, was poor. It most likely was a result of HIV because people who quit drugs start developing all kinds of disease and illnesses. Everything comes to the outside and it is in the wrong place. All the blame on [drug] withdrawal. One of the girls was admitted to hospital. She was not able to hold down her food; she vomited constantly, whatever she ate or drank. She was 45 years old and weighed only 38 kilograms. In two days she was discharged because [the doctors] decided that she did not have "anything". What kind of anything? I do not understand this definition. My child died from rotavirus because she "did not have anything", but if [the doctors] had examined her properly, they would have understood the severity of the situation. Coming back to that woman, she did not have medical insurance so she was discharged in two days. Now, she is dying at home again. This is her situation. What is she supposed to do? The doctor does not know, and I do not know, but a person is dying! And HIV gets in the way. Neglected treatment. This is the stigma in regards to a *narkoman* and an HIV-positive. If a drug addict is also HIV positive, this is the end. He is [less than human]. And no one will look and find out [what is wrong with him]. "What do you expect? He is a drug addict." "What do you expect? He has HIV!" It is better when a person only has HIV, but if he is also a drug addict, all doors are closed to him. They will speak to a tidy and neat [person living with HIV], they will do something for him. But for a drug addict, there is nothing but immediate refusal. But in bigger towns

such as Tartu, they may not throw him out at once. Maybe they will even treat him. (Natasha)

In addition to being a peer counselor, Natasha is also highly involved in the Ida-Virumaa's Narcotics Anonymous, and goes to great effort to encourage IDUs to stop using drugs, help them through drug withdrawal, help them find employment, and tries to convince them to access care. She mentioned to me many times that she will collect and deliver ART medications to PLWHIV who are unable or unwilling to visit the clinic themselves, and she maintains contact with many of them to make sure they are adhering to ART. However, the behaviour of healthcare providers and their reluctance to provide care to vulnerable populations is a difficult challenge for Natasha and other healthcare providers because it is difficult for them to convince a vulnerable person to go to a place where they may be discriminated against. Moreover, PLWHIV talk to one another. They share stories, factual information, and misinformation they have heard with each other. When one of them has a negative experience with a doctor, they share it with their family, friends and acquaintances, which lead to a growing feeling of being discriminated and not wanted.

### **Unprofessional Behaviour and Acts of Discrimination.**

In addition to being talked down to and being denied services, the participants shared many experiences about how healthcare professionals either behaved unprofessionally or openly discriminated against them because of their HIV status. The majority of the participants experienced discrimination and unprofessionalism from healthcare providers in the past and have many friends who have had similar experiences. Some of the following excerpts were presented in the previous subthemes but are being reused to demonstrate the unprofessional behaviour of healthcare providers.

[Doctors] are all the same. Then again, there are some good ones who explain everything tactfully and competently. But there are a few who treat [PLWHIV] very badly. That is why I cannot say that everyone is an asshole. (Victor)

As mentioned at the beginning of the chapter, a doctor told Olga, “Go home and wait, until you die,” when she first learned that she had HIV. This was very interesting and surprising, so during the interviews, I asked the participants, who were healthcare providers, what they thought about these powerful words from a doctor to a patient. It was very interesting that none of them was surprised about the doctor’s statement.

It is not a surprise for me because I know that doctors can say that, and it’s not only related to HIV but also to other diseases. I think that these are doctors that should not be working as doctors. This is unprofessional behaviour, unethical. No doctor or nurse should say that. They do not even have the right to say that to a patient dying from oncology. If a person says that to his patient, he is not a professional doctor. He has breached ethics and regulations. He chose this profession. He must know how to communicate [with patients]. I think it is wrong, but it is [the situation] unfortunately. (Anastasia)

No, it is not a surprise. You can expect [things like that]. Last summer we had a young woman whose mother had complications with her HIV. The doctor invited the girl [to his/her office] and told her that her mother had AIDS [and her life was over]. The daughter thought that this was the end that her mother would die... The daughter came to me and I spoke with her for a while. I explained [HIV] to her and that her mother had to start taking ART, and why she needed the treatment. The girl told me with tears in her eyes that I had explained everything to her so well because before she thought her mother would die soon... [She was first] told that her mother had AIDS and that it was the end. (Valentina)

That Olga’s experience of being told that her life was over and that she should go home and die was not a surprise to the healthcare providers who participated in the study shows that this form of unprofessional communication between doctors and patients living with HIV may be common. It not only highlights a lack of knowledge of HIV and services available for PLWHIV, but also portrays a picture of doctors being unwilling to perceive or speak to their patients as people.

When a doctor discriminates or is unprofessional with a patient because of his or her HIV status, it understandably harms the patient emotionally and psychologically and can greatly impact his or her life. Nadia shared two very powerful stories about how a doctor's unprofessionalism and discrimination harmed a patient living with HIV. The first story was about one of Nadia's close friends who was living with HIV and went to see a doctor. At the time, Nadia's friend had recently been hired as a hairdresser at a local salon. Given the poor economic state of Ida-Virumaa and the growing unemployment, her friend was very excited and grateful to have found a job. However, before she could begin working, she needed to provide her employer with a health certificate<sup>29</sup> from her doctor. While she visited the doctor,

The doctor looked at her and asked, "Are you really going to work as a hairdresser". [My friend] said, "Yes. Why?" [And the doctor responded], "Well tell me later which salon you will be working at so that I will know not to go there."...The doctor told her that. (Nadia)

Nadia's friend went to the doctor's office only to get a health certificate so she could work, but instead the doctor's unprofessionalism and discrimination traumatized her and left her feeling less than human.

[I know the girl well] she is my friend. She is a very emotional girl. [After the visit to the doctor] she went on the street, phoned me, and cried over the phone for two hours. She said, "How can it be? Why?" And if I am a little scared that someone might find out about [my HIV status], she is terrified. [That day] she was terrified to the point of hysteria. She had to be taken to a psychologist who explained to her that nothing bad would happen if someone found out. [My friend] asked [the psychologist] if this is how doctors are supposed to react. If a doctor does not have enough information then who has? If a doctor reacts this way, how will other people?

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<sup>29</sup> The request for a health certificate is very common practice in the Russian Federation and other former Soviet countries. In the Russian Federation, employers and public centers, such as fitness clubs and swimming pools, regularly require individuals provide a health certificate when they are hired or during registration.

If a doctor, or other healthcare provider, who is treating vulnerable people also supports and empowers the cultural stigmas and perspectives of HIV, it is understandable why Nadia's friends, and other PLWHIV, would not want to return to visit that doctor or other healthcare providers.

Nadia's second story is not related to how doctors treat PLWHIV directly, but indicates how their unprofessional behaviour can indirectly impact a person living with HIV. Six years ago, while she was pregnant with her youngest child, Nadia's doctor, who was overseeing her pregnancy, had Nadia tested for hepatitis, and the test identified her as being hepatitis-positive. Nadia did not provide information about which hepatitis she was tested for, only that she was found to have hepatitis. Because of the HIV and hepatitis co-infection, Nadia's doctor told her that she would have to have a C-section.

According to all the analyses, I could have had the labour myself. One month before the due date, she decided to test me for hepatitis. When I came to her, she said, "Darling, we will not have [a natural birth]. You need to have a C-section." I was already 39 weeks pregnant. The doctor had me admitted that day, and I was just in time as I started having contractions. The doctor then told me [I needed a C-section] because she did not work in the sphere [infectious diseases], and that she did not know much about [HIV and hepatitis]. Six months ago, I went to see my [new *infectionist*]. She started doing different analyses and asked me about hepatitis. I told her that the doctor diagnosed me with hepatitis 5 years ago. [My new *infectionist*] asked, "Why 5 years ago? Were you treated?" I told her "No. My [old] doctor said it was not a big deal, period." ... I had been seeing my [old doctor] every six months [since my last pregnancy] and she knew I had hepatitis. Why did she not tell me that I had to take medications, or that I needed to be treated? I am a medical worker, and she tells me [it's not a big deal].

The result of Nadia's first exam must have shown her as being a false-positive, yet it portrays some very troubling behaviour from the doctor who oversaw Nadia's pregnancy. Her doctor received a diagnosis of hepatitis for Nadia, and did nothing. In the six years after her diagnosis, Nadia's doctor did not provide any follow up for the diagnosis. She did not send Nadia for treatment or recommend her for additional analysis. It was not



until Nadia visited her new *infectionist* six years later that Nadia learned that she needed to be treated for hepatitis. Even though the hepatitis diagnosis resulted in a false-positive, the fact that her original doctor did not or would not provide proper follow up with her regarding what she should do about her diagnosis left Nadia very bitter towards doctors in Ida-Virumaa. It also points to another serious situation in Ida-Virumaa. If such a situation could happen between a doctor and a nurse, how do doctors treat PLWHIV who are not healthcare providers? How many others have been diagnosed with life-threatening infections that were dismissed as being ‘not a big deal’?

When they happen, negative experiences with healthcare providers, such as the two Nadia shared, undoubtedly circulate through the PLWHIV’s social circles, and PLWHIV begin to not only feel discriminated against by the healthcare system but also start to judge the sincerity of the healthcare providers. This leads to a growing feeling held by PLWHIV that some doctors may not always be concerned about the patient’s best interests when prescribing treatment. This leads one to wonder why a person living with HIV should see a doctor when the doctor’s own unprofessionalism and discriminative behaviour may result in social, psychological, economical, emotional or physical complications for that person.

### **Lack of Knowledge.**

In addition to the previous ways in which healthcare practitioners acted as a barrier to care, the participants strongly felt that some, but not all, healthcare providers in Ida-Virumaa have a very poor understanding of HIV and how to treat HIV. The participants mentioned that healthcare providers, particularly doctors, would often provide them with misinformation about HIV, or suggest unnecessary lifestyle changes,

such as each person using their own dishes or pregnant women with HIV requiring an abortion. What is very important about this theme is that participants who had the strongest feelings and were most critical of doctors' lack of knowledge about HIV were also healthcare providers.

My family doctor told me that in our family each one should have their own mug, their own spoon. This was told by a doctor! (Marianna)

Not everyone knows that there is antiretroviral treatment; those who have encountered this problem know; those who have not [encountered it], do not know about it. There are even medical workers who do not know that they may get infected by blood or through sexual intercourse. They think, for instance, that if you get into a shower together, you may get infected. If the doctors do not know, then there is no point in discussing it with ordinary people. (Nadia)

Not only do people not know anything about HIV, the doctors themselves do not know anything about that. You come to a family doctor, you talk about this and he does not know anything and cannot help you with anything. And he tells [PLWHIV] so much weird stuff such as that if you have HIV, you need to have an abortion. Why? What is the reason? (Daria)

The participants, particularly those who were healthcare providers, were very frustrated at the lack of knowledge of HIV held by healthcare providers. Nadia's statement, "If the doctors do not know [about HIV], then there is no point in discussing [HIV] with ordinary people" identifies a critical issue for PLWHIV accessing care in Ida-Virumaa. As doctors act as important gatekeepers between vulnerable populations, such as PLWHIV and IDUs, and the general public, they need to be well informed to be able to raise public awareness about HIV, counteract the powerful stigmas associated with HIV and PLWHIV, and work to help control the epidemic. Unfortunately, Nadia strongly felt that *infectionists* also knew very little about HIV.

They treat [us] differently, when they learn [about our status]. Sometimes I even think that our doctors who prescribe us antiretroviral therapy are completely incompetent in HIV. They only know that they have to prescribe those pills and

treatment, and that is it. They do not know anything more. I am talking about *infectionists*. I have this understanding that even though they are saying that you have to take the pills, and that if you do not take them, you will die, so what? They tell this to addicts too: if you take the treatment, you will get your pension. I do not understand. Why do they need this? Do they have some statistics, and they get bonuses based on that? But our *infectionists* do not know anything. (Nadia)

As a nurse living with HIV, Nadia referring to *infectionists* as being “incompetent” and prescribing pills is a very powerful statement as it implies that PLWHIV feel that those who they depend on for life-saving care may not care about their patients living with HIV.

Unfortunately, I was only able to meet two doctors while I was in the field, and they were very knowledgeable and professional about HIV. However, the perspective and frustration held by the participants and the people I spoke with implies that many doctors, not to mention nurses and social workers, know very little about HIV and openly distribute misinformation about HIV to PLWHIV and the general public. In a way, they are promoting and reinforcing the stigmas associated with HIV and PLWHIV. Olga and Valentina both shared stories of when doctors informed a person living with HIV that their death was near. Natasha shared a story that a doctor would only speak to a person living with HIV through a door because of a fear of being infected, and Olga shared a story of how the doctor made her pregnant friend bring her own cushion to sit on every time she visited him. The lack of information about HIV is related to a fear of being infected, which then leads to discriminative or unprofessional behaviour towards PLWHIV. The lack of knowledge about HIV, combined with unprofessional behaviour and discrimination towards PLWHIV, denial of care, and talking down to PLWHIV individually and collectively all represent a serious barrier for PLWHIV who would want

to access care in Ida-Virumaa. Unfortunately, they also perpetuate another barrier to care: the lack of faith in healthcare providers.

### **Lack of Faith in Healthcare Providers.**

The final theme in this cluster is a lack of faith in healthcare providers. Many of the participants either do not trust healthcare providers, or believe that certain healthcare providers do not know or care about what is in their best interest. Because the previous subthemes and theme clusters of this chapter identified, sentiments and examples of stigma, discrimination, unprofessionalism, and sharing incorrect information about HIV with PLWHIV, it should not be surprising that the participants do not trust their healthcare providers, especially as many of them were able to gain access to accurate information from organizations like the EHPV and HIV clinics.

Natasha shared a recent experience she had with a doctor that truly highlights her loss of faith in healthcare providers.

I recently had surgery. When the doctor asked me if I had some disease that he did not know about, I told him that I had hepatitis C, but that I was treating it. I was simply afraid of telling him about [my] HIV. Although the surgeon explained that he was not interested in anything else, I was still afraid to tell him. I understood that the outcome of my surgery depended on that. [I was afraid] that I may not wake up after [anesthetics] because [the surgeon and nurses] could have left me to bleed to death out of fear of HIV. I did not want his personal attitude to become worse. I simply wanted to be a regular patient. It was fear from my side and it was fear from [his] side. How do you live without fear? (Natasha)

Natasha's story demonstrates how her lack of trust towards healthcare professionals made her very reluctant to share her status with them. Natasha has been living with HIV for nearly twenty years and for the past few years, she has been working as a bridge between IDUs and PLWHIV and the healthcare system. She has a poster of all the different antiretroviral medications prescribed in Estonia on her office walls and knows the

different combinations and schemes offered in Estonia, believing that she knows more about HIV and ART than many healthcare providers in Ida-Virumaa, which was not an idle boast. Of all the people I met in Estonia, she was the most open about her status and tried to convince people to be open about their status. Nevertheless, she was still afraid that if she had shared her status with the surgeon, he might have left her to die. Marianna shared a similar experience of fear while she was undergoing her first C-section.

When I was pregnant with my first child, [after contracting HIV], I prayed every day that the child would be born healthy. During the C-section, they were trying to sedate me for two hours and it was not affecting me. It was a complicated procedure, particularly morally. I was sitting there, naked, like some kind of monkey. And all of the doctors looked at me frowningly. I could feel that their attitude was not sincere. They told me that I was doing well, but in reality I felt that they wished me bad. (Marianna)

Although it may seem an unnecessary fear, that a doctor would never leave his patient to die, there is, unfortunately, a precedent of similar issues in Ida-Virumaa. Natasha lost her daughter, who was eight, due to a doctor's negligence with her rotavirus infection. Nadia also shared with me the story of how her husband died from an HIV complication because of negligence and the design of the Estonian healthcare system in Ida-Virumaa.

My [*infectionist*] only started treating me well after she killed my husband, so to speak. Well, figuratively, I mean. I guess, it is healthcare's fault that people who are in infectious disease hospitals are not taken anywhere without a doctor. But in our hospital there is only one doctor working on-call during the weekend. [I don't know if the system changed recently]. But it was in the same hospital 6 years ago...[and only a cardiologist was working]. [While at the hospital] my husband fell into a coma. I phoned the cardiologist, but his phone was switched off. So I called the nurse attending to my husband, and she told me he "withdrew". I asked, "What do you mean?" "Was he angry and walked out of the hospital?" She said, "No. He is in a coma." It was said so casually as though he had gone for a smoke. Like, "so what that he is in a coma?" Of course, my first reaction was to ask for the doctor. She said that they had only one doctor, and no one else. There was only one cardiologist for the whole hospital and no other doctors. I started calling hospitals in Tallinn and Tartu. Everyone said they needed a transcript from [my

husband's] *infectionist* because they needed a confirmation that [my husband] was not contagious. So it turns out that our hospital did not have an intensive care ward, and other hospitals did not admit patients from infectious disease hospitals. So he fell into a coma and was just lying there with other people. You understand [he had no medical equipment], so he died the next day. I made all of the arrangements [for him to be transferred]...the medical equipment and the medical team. I made all the arrangements, and [the doctors in Tartu and Tallinn] told me that I only needed to bring a form from the [*infectionist*]. I wanted to get that paper from the cardiologist [on duty], but he said, "I am not an *infectionist*. I cannot issue such forms." I made all the arrangements, but as it was on a weekend, everything was postponed until Monday. [My husband] died on Sunday. (Nadia)

The minimal staffing of hospitals is still common practice in Ida-Virumaa. The bureaucracy of the Estonian healthcare system prevented Nadia from being able to have her husband relocated to a larger hospital in Tartu or Tallinn. However, it is also important to realize that, while he was admitted in critical condition, the hospital staff did not provide him with adequate services to prolong his life. Even after he fell into a coma, he did not have an I.V. or a heart monitor. Nadia strongly believes that he did not have access to these basics of hospital services because of the *infectionist*'s stigmatization of PLWHIV.

So there is no point in talking about how other doctors treat us. When [my *infectionist*] realized what she had done... when I first brought him [to the hospital] he was in such a [critical] state that he needed to be admitted into intensive care... she realized, as she was the head of the department, that her employees had been negligent. She must have been scared that I would go somewhere and complain [about the situation]. Only then did she start treating me more or less like a normal person. [She started to ask], "[Nadia] how are you?" "How do you feel?" Maybe she started asking because I was pregnant, but she was never like that before [my husband died]. (Nadia)

Negligence and Estonia's healthcare bureaucracy may have allowed her husband to fall through the cracks in the system and die, but the stigmatization of HIV and doctors' attitude towards PLWHIV also played a role in the death of Nadia's husband. As Nadia

was an experienced nurse, she knew that her husband needed to be admitted into intensive care, but her *infectionist* did not admit him, and was not available to sign the paperwork to have him transferred.

Participants, most of whom were well informed about HIV, were also very frustrated that doctors, particularly family doctors, knew less about HIV than they did. The lack of knowledge combined with the stigmatization of PLWHIV by healthcare providers resulted in many of the participants believing that doctors do not want to look after people living with HIV. What was particularly concerning is that the lack of trust and faith extends to *infectionists* and ART as well as other healthcare providers.

We have clients who have to travel a long way to visit a family doctor. [But] when a family doctor sees them, they try not to do any expensive medical treatments for people with addictions. For example, if a drug addict has been an addict for a long time and is in a situation where he needs an expensive cardiovascular surgery or a liver transplant because of hepatitis, the doctors try to take their time, as long as possible, to postpone the surgery. They are looking and sniffing around, listening to how stable the person is, and if the surgery is needed and if there will be any effect from this. Of course, you may take the doctor's side because it is a lot of money and labour that could be allocated to somebody who needs it more, to a person who values their life more than a person who only values a 5-minute pleasure. But anyway, at this point people have bad relations with doctors. HIV-positives feel discriminated even if they are focused on treatment and recovery and are not using alcohol or drugs. (Natasha)

[*Infectionists*] are trying to force people into the cheapest treatment. There was a situation when I had an allergy to [one of the ART medications]. [My *infectionist*] said, "Well we have this [drug]." I asked her why she did not give it to me earlier. [She said.] "Because it is expensive." I understand that the government wants to save money, but they are not saying anything [about other drugs], they are hiding it. (Nadia)

I do not trust [my *infectionist*] [and my friends and acquaintances] do not trust her. I know that there have been many cases where people change their *infectionists* because of how poorly they were treated (Peter).

PLWHIV are not given information about [ART]. I have been taking ART for a long time. But all I know about ART is learned from working at [*confidential location*] because people come here. A person goes to his *infectionist* and she

does not even tell you (pause) She prescribed me Stokrin, which made me feel so bad that I could not even [function]. She warned me that there might be vertigo, and that I should take it before I went to bed because I would fall asleep instantly. She told me that there might be side effects, but she did not tell me that if I felt very bad, I could come back and they would change my treatment. She did not tell me that there were a lot of different treatment schemes. She did not tell me this, and I do not know why. (Nadia).

It should not be surprising that PLWHIV are cautious of or do not trust healthcare providers in Ida-Virumaa. It is only understandable that, after years of discrimination, unprofessional behaviour, denial of services and poor understanding of HIV, PLWHIV would have bad relations and doubt the sincerity of the people who control treatment. Feeling that they are being treated as less than human or unworthy would make anybody reluctant to return for care because who would want to return to a place where he or she would feel clearly unwanted?

Some of the participants are also perplexed that they know more accurate information about HIV than healthcare providers, including *infectionists*. This has led to many of the participants feeling that healthcare providers are not competent when it comes to HIV and treating HIV. Moreover, some of the participants were very knowledgeable of the different ART schemes available to PLWHIV in Estonia, yet many of them felt that *infectionists* were unwilling to change treatment schemes if a patient was experiencing complications from the side effects.

Another area of tension between *infectionists* and PLWHIV is the Government Disability Pension for PLWHIV. The disability pension<sup>30</sup>, which many PLWHIV and IDUs qualify for, is a small monthly stipend of €80 - €160. The amount an individual will receive is based on that individual's health status, which for PLWHIV is determined by

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<sup>30</sup> The pension system is currently being reviewed and a new program is in the process of being designed. The pension system has been widely regarded as a barrier to ART adherence and represents both an area of frustration for healthcare providers and a necessary lifeline for marginalized PLWHIV who are also IDUs.



measuring the patient's viral load and CD4 count. If an individual has a poor health status, low CD4 count and poor viral suppression, he or she will receive a larger amount from the pension, while if the patient has a high CD4 count and good viral suppression, he or she will receive a smaller pension. The purpose of the pension is to provide financial aid to PLWHIV until they are healthy enough to rejoin the workforce, and once an individual reaches a specific stable health threshold, he or she will no longer be eligible for the pension. However, the disability pension is very problematic in Estonia as it often becomes an important, if not the only, source of reliable income for PLWHIV who are also struggling with addiction. Because the poorer health status correlates with higher monthly pensions and good health correlates to smaller or no pensions, many PLWHIV do not properly adhere to ART so that they get the largest monthly pension as possible. In its present form, the Disability Pension rewards non-adherence to ART and losing the pension is seen as a punishment for adherence.

The disability pension has become a slight obstacle for the Estonian Government and *infectionists*, as the low adherence rates to ART means that a lot of government money, approximately €5000 per person living with HIV, is not being effectively spent because many of those receiving ART are doing the following: throwing it away, not using it or selling pills to Russian smugglers<sup>31</sup> to ensure they are able to get the largest pension possible. This issue has resulted in a political response to reform the pension, and a growing frustration amongst *infectionists* and healthcare providers. However,

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<sup>31</sup> Valentinna and Natasha told me that it was very common for some PLWHIV, particularly IDUs, in Ida-Virumaa to sell their ART medication to Russian Smugglers. As The Russian Federation does not supply ART to PLWHIV and the price of ART is very high, the smuggling of ART medication provides an additional opportunity for PLWHIV to make a little extra money.

participants felt that *infectionists* are using the disability pension as a way to hold them “hostage” to a particular scheme of ART.

They tell drug addicts that if you do not take your pills, they will not give you a pension. Drug addicts are worried about every penny, any income. So this is how they are “hooking” them. But all the drug addicts I talked to take these pills only a couple of weeks before their checkup, before their pension and quit [after the check-up]. They do not take them anymore. (Peter)

They tell [drug addicts], “If you take [ART], you will get your pension.” (Nadia)

The perceived use of ART as a “hook” on impoverished drug users to gain access to a disability pension, combined with the discrimination experienced by PLWHIV, has led to some poisonous relationships between PLWHIV, IDUs, and *infectionists*. When *infectionists* use removal of pension as an incentive to adherence to ART, people who have the pension feel even less willing to adhere to ART out of fear of losing the pension for being too healthy, and feel bullied and discriminated against by the *infectionist*.

The impact of this loss of trust and poor relationships can be seen in the following experience that took place in 2008, which was shared by one of the participants. In the following example, the participant’s name and location has been withheld or altered. The reason for this is that the following excerpt represents only how the participant perceived the situation and that the *infectionist* involved could be easily identified, which may result in negative consequences for that *infectionist*. It also needs to be said that prior to this interaction between the *infectionist* and the participant, the participant had a very positive relationship with the *infectionist* and often visited the *infectionist* without the need of an appointment. At the time of the incident, the participant was also an active intravenous drug user.

At the time, I had the disability pension connected with HIV. My pension was coming to an end and I had to retake all the analyses for [my pension to be renewed]. I went to my [*infectionist*]. I told [my *infectionist*] that my pension was expiring and that I needed to prepare the documents for the extension. There were a lot of us [who needed the extension], and we were talking to each other. Before I entered [my *infectionist*]'s office, I saw that all the people in the waiting room were sitting with wrapped presents. And I thought, what? Was something wrong? Maybe it was someone's birthday and they were all going together afterwards. Then, I asked one of the girls [who was also my friend] what was going on. She explained to me that they needed to pass the board and everybody there needed their pensions extended. She started telling me that she brought a gift for the [*infectionist*], and said that the doctor liked little cups, little mugs, and little gift sets. My friend asked me whether [the *infectionist*] would like her present. I said that I was only hearing about [giving her gifts] for the first time. She said, "Do you see the whole line here? Everybody brought what they could. I became so angry, and I felt like such a fool. I did not know that I had to bring something, and I also had financial difficulties at the time. I had no means to get [my *infectionist*] a present. Even if I learned at that moment, as I was sitting last in line, I could have bought something before it was my turn. But, as I already said, I had financial troubles, and I was very worried that [he/she] would send me away. [While waiting, I saw] that everyone who came with presents came out [of the *infectionist*'s office] happy."

While gift giving is a very important cultural practice, The Russian Federation and the Soviet Union has a long history and practice of bribing/giving gifts to officials to gain access to certain benefits. Unlike other post-Soviet countries such as Russia and Ukraine, Estonia has done a lot to limit and punish corruption. In this situation, however, the participant and the other people waiting to see the *infectionists*, many of whom were also IDUs, thought that they needed to bribe the *infectionist* to be able to receive the pension. This perceived necessity to bribe in order to receive a state benefit not only highlights the power relationship between the *infectionist* and the participant but also how poorly each participant viewed the *infectionist*. The story then continued,

And when I entered the office, the doctor looked at me in such a way. I did not make an appointment, but we all came without making appointments as we were like loyal customers to [the *infectionist*]. When [he/she] saw me [without a present], [he/she] asked, "Do you have an appointment?" I answered [my *infectionist*], "I need to extend my disability as soon as possible." [He/she] then

told me, “If you do not have an appointment, go away! Can you not see how many [patients] I have waiting? I do not have time for you.” I then said, “But I urgently need to reapply for [my pension]!” [He/she] replied, “I do not have time, I have other patients and there is nothing I can help you with.” I was puzzled. I went out and decided to do something and to arrange some kind of present [for a bribe].

The limited number of *infectionists* in Ida-Virumaa combined with being marginalized within society meant that this participant was very afraid that if he/she did not meet this *infectionist* and get her pension renewed on that day, she would lose her pension. The *infectionist* had been very inclusive in the past by seeing the participant whenever he/she called, but on this occasion the *infectionist* was unable to see him/her. Not realizing this and worried about the complications the loss of the pension would have for his/her family, the participant felt it was critical to find some kind of bribe for the *infectionist*.

[I got] a bottle [of rum] and a box of chocolates [from my mother]. I grabbed them and ran back to the doctor’s, because it was really urgent. [When I got back], [my *infectionist*] asked, “What do you want?” I did not know how to bribe, did not know at all. So I clumsily gave the bag to [him/her]. [What happened next] is funny for me now, but it was far from funny at the time. [My *infectionist*] looked inside the bag. I guess [he/she] did not like what I brought [him/her]. Maybe it was not [his/her taste of alcohol]. Maybe I should have bought something [more expensive] if I had money, but I took what I had. [He/she] put the bag aside and said, “What are you giving me? I do not need it.” I got so offended by that. So I took the bottle [of rum] and smashed it on the desk. And I said, “I only had enough money to buy you this and you do that to me?”

As gift giving and bribing is very important in Russian culture, the blunt refusal to accept a gift or bribe also has a very strong cultural meaning. By bluntly refusing to accept a gift or a bribe for service, one individual is telling the other that he or she is less than human (*vtoroi sort*)<sup>32</sup>, not worthy of his or her time or help, and he or she should not be associated with.

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<sup>32</sup> Second grade/Второй сорт

In this situation, the participant, already afraid of losing the pension, was not prepared to have his/her bribe dismissed by the *infectionist*, that he/she not only felt insulted but also deeply hurt by the rejection.

I called [him/her] some nasty things and profanities and ran out, and she followed me. [He/she] was standing, shaking off the rum, because some splashed on [him/her], and [he/she] told me, “Alright, let’s go and see what I can do.” I answered, “I do not need it anymore!” [He/she] had to talk me into it because I was proud. In the end [he/she and a nurse] calmed me down and extended the pension. But it was very difficult for me at that time because others brought bribes to [him/her] and [he/she] did not like mine.

I [transferred to another *infectionist*’s] the first chance I got. Now, [he/she is my *infectionist* again], and I come and see [him/her] anyway. [He/she] smiles and asks how I am doing, and I say I am doing fine. [When I started seeing him/her again] I was still puzzled and offended. I brought [him/her] the last of what I had. I took it from my mother and [he/she] told me such a thing.” [One day he/she explained to me that [he/she] does not have the right to take bribes... I am very ashamed of what I did, and I guess that [he/she] must as be well.

Although this story only represents one side of the event, it does highlight how PLWHIV, particularly IDUs, see and understand healthcare providers and the state pension available to some people living with HIV. What was particularly interesting in this exchange is that the participant and the other patients visiting the *infectionist* that day felt that they needed to bribe the *infectionist* to renew their disability pensions. I spoke with many healthcare providers while in the field about bribery, and they could not believe that an *infectionist* would ever accept or demand a bribe to authorize a pension for a person struggling with addiction. From speaking with these healthcare providers, I do not believe that the *infectionist* in question would have accepted bribes to authorize a person’s pension. At the time of the incident, this *infectionist* had a positive relationship with the participant, and the participant would often visit her without an appointment. Like all *infectionists* in

Ida-Virumaa, the *infectionist* was very busy, and most likely was not able to accommodate a drop-in appointment on that day.

What is important, however, is that the participant and the other patients felt that they needed to bribe the *infectionist* to get the pension. Even though the participant did have a positive relationship with the doctor and could visit the doctor at his/her own convenience, the participant still felt that without a bribe, he/she would not be able to get his/her pension. When the *infectionist* refused the bribe, he/she became enraged and abusive as the pension represented the only stable income the participant had. The rejection of this bribe also identified other difficulties for PLWHIV in Ida-Virumaa. After this event, the participant transferred to another *infectionist's* the first opportunity he/she had, but was forced to return to the original *infectionist* due to government cuts in the region. Because of their past history together, the participant feels frustration, anger and shame every time he/she visits the *infectionist* and is less hesitant to visit the *infectionist* as a result.

Unfortunately, it appears that the relationship between *infectionists* and PLWHIV, particularly IDUs who are living with HIV, has taken yet another negative turn. On March 1<sup>st</sup> 2016, while I was in the field, the Ministry of Health, on the advice of Estonia's National College of *Infectionists*, implemented a new contract that each person living with HIV must sign in order to receive ART. One of the lines of the contract, presented in Appendix III, describes that if a patient fails to adhere to ART, meaning that the patient does not have a significantly improved CD4 count and viral suppression, the *infectionist* has the right to remove that patient from the government-paid ART program. The result of such a decision would mean that the patient would be responsible to pay for

his or her own ART. As the Estonian government pays an estimated €5000 per person and Estonia has very high non-adherence to ART rates, this policy has been implemented to be cost-effective and increase adherence. However, the implementation of this contract has only resulted in enraging both PLWHIV and the agencies that provide services to PLWHIV. Natasha described it to me as being open discrimination against PLWHIV because you would never force a person with cancer or tuberculosis to sign such an agreement<sup>33</sup>. The EHPV staff had very serious concerns about this new contract and strongly believed that all it would do is further push marginalized PLWHIV away from healthcare providers, increase non-adherence to ART, and create an image of discrimination between the *infectionist* and patients.

## Summary

The results of this study have identified very powerful cultural metaphors and understandings of HIV and PLWHIV that provide the essence of the symbolic meaning of HIV stigma. The participants' shared testimonies not only demonstrated the power HIV stigma has on their individual lives, but also how HIV stigma acts as a barrier to accessing care and by extension adherence to ART. The negative stigma associated with PLWHIV means that those who are publicly identified as having HIV are very likely to lose employment and/or be ostracized from their communities. Moreover, there is also the risk that their children and other family members will inherit the label of being HIV positive. This risk of discrimination means that many participants are unwilling to access care, especially in Narva, out of fear of being seen by someone.

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<sup>33</sup> Prior to leaving the field, the EHPV and other healthcare providers began searching for legal options to challenge this new policy.

Unfortunately, the discriminatory behaviour of many healthcare providers also presents a challenge to PLWHIV who want to access care. The participants' testimonies identify that PLWHIV are frequently denied adequate care, belittled, and encounter unprofessional behaviour when they access care from healthcare providers. Moreover, some healthcare providers often tell them misinformation about HIV, which they know to be false, and openly promote the cultural metaphors of HIV and HIV stigma. These conditions have led to the erosion of trust between PLWHIV and their healthcare providers.

The combination of these barriers to care provides valuable insight into why ART adherence continues to remain low in Estonia, for how can people be expected to adhere to ART when they are neither willing to risk accessing care, nor want to be discriminated against by healthcare providers. The combination of HIV stigma, fear of disclosure, discrimination from healthcare providers, and state policies, have fostered an environment of structural discrimination that limit PLWHIV ability to access care.



## **Chapter Five: Discussion**

This study began with the purpose of documenting the contemporary perceptions and cultural metaphors of HIV held by PLWHIV in Ida-Virumaa, Estonia, and sought to understand how and if HIV stigma influences care-seeking behaviour for PLWHIV. The findings of this study not only identify the cultural meaning of HIV and PLWHIV held by the PLWHIV and the general public, but also clearly indicate that HIV stigma, discrimination, and fear of discrimination have serious repercussions for PLWHIV in Ida-Virumaa that make accessing care a very daunting and risky endeavor which can result in serious negative social, economic, psychological, and emotional consequences. In addition to the cultural metaphors of HIV and HIV stigma, fear of disclosure of one's HIV status and discrimination by healthcare providers were identified as representing serious barriers to care and ART adherence for PLWHIV in Ida-Virumaa. Although fear of disclosure and discrimination from healthcare providers may not be the only stigma-related barriers to care in Ida-Virumaa, the findings of this study indicate that they present a significant challenge to PLWHIV accessing care or treatment and to their willingness to return for additional care or treatment. This chapter will summarize the study's findings, examine how they relate to the literature, and examine how the cultural metaphors of HIV and PLWHIV and the identified barriers to care create and perpetuate an environment of structural discrimination for PLWHIV in Ida-Virumaa.

### **Cultural Metaphors of HIV and Disease Stigma**

The effects HIV stigma and stigmatization on the wellbeing and care-seeking behaviour of PLWHIV are well established in the literature. However, despite some overlapping similarities, how far HIV stigma is experienced, understood, and perpetuated

by a population or society varies between populations, geo-political regions and cultures (Parker & Aggleton 2003, p. 14). Because of the differences between populations and perspectives of HIV, stigma, and discrimination, it is important to understand the cultural metaphors of HIV and PLWHIV and how these cultural metaphors foster the creation of a symbol of HIV and PLWHIV, which then enables the stigmatization of and discrimination against PLWHIV within that specific location, culture and society.

According to the participants, the general population of Ida-Virumaa seems to hold many different misconceptions about HIV biology and treatment. Although this is not a problem unique to Ida-Virumaa, participants expressed a shared perspective that the people of Ida-Virumaa believe HIV can be transmitted through physical contact or by touching something used by a person living with HIV. This perspective of HIV transmission is most likely a combination of a cultural belief and understanding of *microbii* and a poor understanding of the basics of HIV biology. Although some of the participants and people I met in the field did mention that there was a general understanding that HIV is transmitted through intravenous drug use, unsafe sexual practice and promiscuous lifestyles, there is still a strong belief that people can contract HIV like one could contract the flu because HIV is *microbii*. Moreover, that HIV is associated as being a death sentence without a cure also identifies a lack of public awareness of HIV, ART, and the fact that people can live a full life with HIV.

What was particularly interesting is that many of the participants expressed that these misconceptions of HIV are openly held and promoted by some healthcare providers in Ida-Virumaa. That some healthcare providers in Ida-Virumaa were telling PLWHIV and family members of PLWHIV these untruths about HIV, particularly the need for

PLWHIV to have separate dishes, was a theme regularly encountered in the field when I spoke with PLWHIV, healthcare providers, EHPV staff and volunteers, and members of the community. As healthcare providers act as public authorities and gatekeepers to health information and treatment, the continued promotion of inaccurate information about HIV biology and treatment by some healthcare providers implies that this understanding of HIV is a well established cultural belief in Ida-Virumaa; one that would be very difficult to change.

What is equally problematic is that, based on the participants' testimonies, the general public, including healthcare providers, is apathetic towards HIV and is not interested in learning about HIV. The notion is that unless an individual is directly affected by HIV, meaning he or she either became infected with HIV or a family member or close friend became infected with HIV, that individual would not be interested in learning about HIV. Moreover, the mentality of "It is no concern of mine" also implies that people not affected by HIV are not only unwilling to learn about HIV but may also believe that they should not learn about HIV.

The participants also expressed that both the general population of Ida-Virumaa and healthcare providers are very afraid of HIV. The fear associated with HIV apparently is so strong that some trained, experienced healthcare providers are not only unwilling to speak to an HIV positive patient face-to-face, but go so far as to sterilize their offices after a person living with HIV leaves and avoid examining the new born baby of a person living with HIV. Although such behaviour may be difficult to believe, the participants frequently mentioned that people are afraid of contracting HIV, and for some healthcare providers in Ida-Virumaa, this fear of contracting HIV suppresses basic knowledge of

disease transmission that healthcare providers, particularly doctors, should have. Furthermore, there also appears to be a fear of being tested for HIV as healthcare providers and EHPV encounter great difficulties trying to recruit and encourage individuals to be tested for HIV.

The fear and sense of apathy towards HIV shared by the participants are very interesting because a question that emerges: Are people afraid of contracting HIV or are they afraid of being associated with HIV? In other words, are individuals afraid of the disease itself or are they afraid of all the negative consequences that may arise if they are publicly associated with HIV? Remembering that disease stigma consists of all the negative cultural and social metaphors associated with a disease and that stigma is a language of relationships where one individual is labeled as a deviant while at the same time reinforcing the cultural metaphor of being acceptable, the likely answer to these questions is both. However, the cultural metaphors of HIV and PLWHIV combined with the fear and apathy towards HIV and PLWHIV identify the relationship between stigma and power within Ida-Virumaa and Estonia as a whole.

Remembering that the participants of this study were all ethnic Russians, these metaphors of HIV and PLWHIV enable the creation of a theory of HIV illness for the Ethnic Russians of Ida-Virumaa, and perhaps Russian culture as a whole. Where as the term disease refers to the biological, etiological and medical knowledge of a biological related phenomenon, illness is a social and cultural construct of how a population perceives and understands the etiology of a biological or social disease (Alonzo & Reynolds, 1995, p. 305). To the ethnic Russians of Ida-Virumaa, HIV illness is perceived as follows: 1) an illness that causes a rapid death, 2) one that is untreatable, 3) a disease

of *narkomani*, and 4) HIV is *microbii* which can be transmitted from one person to another through direct contact with or being in close proximity to a person living with HIV.

In addition to this cultural perspective of HIV, a clear metaphor of a person living with HIV also emerged from the data. To the general population of Ida-Virumaa, a person living with HIV is viewed as a *narkoman*, that is, as less than human, deviant, not worthy of society, and is responsible for his or her HIV status. This cultural metaphor of HIV is, according to a participant, also symbolically powerful in that regardless of how an individual contracted HIV, he or she is still responsible for the contraction and, thus, all of the symbolic meaning still applies to that individual. Moreover, because of the symbolic association between HIV and intravenous drug use, the symbolic power of being labeled HIV also implies that no matter what an individual does with his or her life, he or she may never be able to “shed” the metaphor associated with having HIV.

Cultural metaphors of HIV are often associated with the stigmatization of those with the disease for a variety of reasons, and these reasons seem to be universal. Alonzo and Reynolds (1995) argue that the stigma associated with HIV and AIDS are rather universal and PLWHIV are stigmatized for their illness because of the following perceptions: HIV/AIDS is 1) associated with deviant behaviour, 2) seen as been the responsibility of the individual, 3) seen to be immoral and associated with deviant behaviour, 4) perceived as being contagious and a threat to the community, 5) associated with an undesirable form of death, and 6) poorly understood by the lay community and viewed negatively by healthcare providers (Alonzo & Reynolds, 1995, p. 305). The cultural metaphors of HIV and PLWHIV identified in this study closely follow Alonzo

and Reynolds' model. Despite the recent demographic changes in the epidemic, HIV in Ida-Virumaa is still primarily associated with intravenous drug use and is seen as being a disease of drug users. Although no metaphor of HIV as a punishment emerged from the data, this study identifies that PLWHIV in Ida-Virumaa are widely seen as being responsible for their condition, regardless of how they contracted HIV. Although limited time in the field made it difficult to accurately identify the perspectives of HIV promoted by the Russian Orthodox Church in Ida-Virumaa, this study was able to identify that PLWHIV in Ida-Virumaa feel that others see them as being immoral, amoral or deviant. HIV is understood as being an inevitable death sentence without cure or treatment, and PLWHIV are perceived as being infectious as HIV *microbii* can easily spread from one person to another. Finally, the data also identified that the participants had many negative experiences when accessing care from healthcare professionals and they hold strong feelings that some healthcare providers see them as being unworthy of their services.

These cultural metaphors can be identified as stigma because they form the symbolic meanings of PLWHIV and HIV ascribed to PLWHIV, regardless of how an individual contracted HIV, labeling them as being socially deviant, and that the general public and healthcare providers reinforce these cultural metaphors. These metaphors also limit the life chances and opportunities for people living with HIV in Ida-Virumaa as disclosure of their status to the community results in the high probability of loss of employment and ostracization. Moreover, the fear of being publically identified as having HIV makes PLWHIV less willing to access care. Healthcare professionals are also openly promoting these metaphors, and, by doing so, are empowering and enabling HIV stigma discrimination against PLWHIV.

Although this study represents the first to examine the influence of HIV stigma on PLWHIV's care-seeking behaviour in Ida-Virumaa, the study's findings build upon the established literature on cultural perspectives and metaphors of HIV in post-Soviet countries, the influence of HIV stigma on care-seeking behaviour, and on the effects of experienced and perceived discrimination by healthcare providers against PLWHIV. The cultural metaphors and stigma of HIV, PLWHIV, at-risk populations and disease stigma held in Ida-Virumaa are similar to the perspectives held in the Soviet Union and the Russian Federation (Feshbach, 2006; Goodwin et al., 2003; Hønneland & Rowe, 2005; King, Maman, Bowling, Moracco, & Dudina, 2013; Rhodes et al., 2006; Sarang, Rhodes, Sheon, & Page, 2010; Wallander, 2006; Zigon, 2011). However, there is one important difference between Ida-Virumaa and the findings of studies conducted in other post-Soviet countries. While other studies investigating HIV stigma and discrimination in post-Soviet countries identified the Russian Orthodox Church (Zigon, 2011), the police (Mimiaga et al., 2010; Rhodes et al., 2006; Sarang et al., 2010), and state policies (Feshbach, 2006; Wallander, 2006) as being state agents of discrimination against PLWHIV and promoting negative cultural metaphors of PLWHIV, the participants of this study asserted that healthcare providers were perceived as being responsible for promoting HIV stigma and discriminating against PLWHIV. When asked, participants described that neither the church nor police promoted HIV stigma or discrimination against PLWHIV. Moreover, many had relatively positive attitudes towards the government's actions to provide support and treatment for PLWHIV in the form of ART and pensions. However, nearly all the participants held that healthcare providers promoted negative metaphors of HIV in the community, reinforcing HIV stigma, and

openly discriminated against PLWHIV who came to see them, denying them services and actively using the threat of removing individuals from the disability pension and the state-sponsored ART program.

The cultural metaphors of HIV expressed by the participants and the volume of discrimination by healthcare providers and members of the community imply that HIV stigma and discrimination are seriously influencing the life of PLWHIV in Ida-Virumaa. They also imply that there is structural discrimination designed to limit the chances of PLWHIV living in the community and their ability to access care.

### **Barriers to Care**

HIV stigma's influence on care-seeking behaviour and adherence to ART is a very complex phenomenon, and is often only one aspect of a constellation of factors that influences whether or not an individual will regularly access care or adhere to ART. That being said, this exploratory study identified two ways in which HIV stigma influences care-seeking behavior of PLWHIV in Ida-Virumaa: fear of disclosure of HIV status and discrimination by healthcare providers. When I asked the participants who were living with HIV what represented the greatest challenge in accessing care, they all stated the fear of their HIV status becoming public knowledge and behaviour of healthcare professionals were the biggest deterrents to accessing care. These perspectives were further supported by the participants who were healthcare providers and by the EHPV staff and volunteers who I spoke with while in the field. As a result, PLWHIV in Ida-Virumaa are very cautious about where they access care. Both of these barriers to care not only present a serious challenge to Estonia's efforts to control the HIV epidemic but also act to undermine the efficacy of ART programs in Ida-Virumaa.



### **Fear of Disclosure.**

The symbolic power associated with HIV stigma seriously influences where a person will access care and/or if he or she will actually access care. The combination of the negative stigma associated with PLWHIV and the culturally acceptable practice of publicly chastising people or groups seen as being deviant means that a person identified as being PLWHIV could experience severe negative economic, social and emotional consequences including the following: loss of employment, emotional and/or psychological abuse, becoming and/or having ones family become social outcasts, and physical violence. It is therefore understandable that PLWHIV would be very cautious of where and when they access services.

HIV stigma, fear of disclosure and discrimination have been well established in the literature as significant barriers to accessing care and ART adherence (Calabrese et al., 2015; Castro & Farmer, 2005; Duffy, 2005; Makoe et al., 2009; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009; Wasti, 2012). This study found that fear of being publically identified as having HIV represents a serious barrier to care in Ida-Virumaa, and these findings coincide with those of other studies that examined fear of being identified as having HIV in other post-Soviet countries (Y. Amirkhanian et al., 2011; Y. A. Amirkhanian, Kelly, & McAuliffe, 2003; Balabanova, Coker, Atun, & Drobniewski, 2006; Bobrova et al., 2006; King et al., 2013; Mimiaga et al., 2010; Rhodes et al., 2006; Rhodes et al., 2012; Sarang et al., 2010; Shilovskaya; Zigon, 2011). The similarities between this study's findings and those of the literature suggest that fear of being publicly identified as having HIV and of the discrimination that may result represents a significant barrier to accessing care and ART

adherence for PLWHIV living in post-Soviet countries. The coinciding findings of this study and those of others studies examining HIV stigma and barriers to care conducted in Eastern Europe and Central Asia are very troubling because they lead to the conclusion that PLWHIV in one of the fastest growing regional HIV epidemics are afraid of accessing testing, care or treatment out of fear of the social, economic, psychological, or physical consequences that may result as being identified as having HIV, which will only hinder efforts to control HIV incidence in the region.

In Ida-Virumaa, the fear of disclosure of HIV status represents a serious challenge for PLWHIV, healthcare providers, and policy makers because every time a person living with HIV needs to access an *infectionist* to acquire more antiretroviral medication or any other type of care, he or she faces a very complicated dilemma. That individual needs to choose between obtaining treatment for an illness they do not feel, or risk the severe consequences of being identified as being *spidoznii* and *narkoman*. Unfortunately, as the symptoms of HIV are only truly experienced by an individual at the onset of AIDS, many individuals are choosing not to access care. The influence of the fear of disclosure of HIV status on care-seeking behaviour is visible in examining the differences between Narva, Kohtla-Järve and Jõhvi.

Even though the fear of disclosure was expressed by all of the participants, what was very interesting was that there was a clear difference between the attitudes and perspectives of the Narva participants and the Kohtla-Järve and Jõhvi participants regarding accessing care. Although all participants who are living with HIV were concerned with the disclosure of status, participants from Narva saw location of services and fear of disclosure as a bigger barrier to care than those in Kohtla-Järve and Jõhvi.

The difference in perspectives is related to the location and layout of the HIV and ART clinics in both communities. The city of Narva has two centres that provide care and ART for PLWHIV, the Narva Hospital and the private Linda Clinic, which is run by the AIDS Health Care Foundation. The Narva Hospital has the city's only full-time *infectionist*, who sees between 500 and 600 HIV patients. The hospital's HIV clinic is located in the main building and has a sign that identifies it as an infectious disease office. The current layout of the hospital means that any person who tries to access the *infectionist*'s office risks being identified by hospital staff, patients, and visitors. Because the location of the *infectionist*'s office in the hospital is common knowledge, people who enter the office are associated with being HIV-positive. The Linda Clinic, in contrast, is located in a small office on the 6<sup>th</sup> floor of an old Soviet-era factory office adjacent to an abandoned factory. The building also hosts a large variety of small business, a café, and lawyer offices. The floor the clinic is located on also receives very little foot traffic, compared to the hospital. Unless someone sees you get off the elevator and ring the clinic's doorbell, no one will notice you. Despite its safer location, the Linda Clinic only has one part-time *infectionist*, who visits the clinic only once a week, yet the clinic has a small team of nurses, a social worker and peer-counselors who offer services to clients five days a week.

In contrast, the towns of Kohtla-Järve and Jõhvi share a hospital, HIV and ART clinics. The hospital, HIV and ART clinics are all a part of the same centre, yet the HIV and ART clinics are located in a small old building that is separate from the rest of the hospital, with its own discreet entrance. Unless someone is either purposely sitting in front of the HIV and ART clinic to see who goes in or is simply strolling around the

hospital, no one at the hospital will be able to see or identify an individual entering the HIV clinic. If a patient does not wish to travel to the hospital, located in the Ahtmae village of Kohtla-Järve, he or she could visit the polyclinic in the main town of Kohtla-Järve where another *infectionist* has recently returned and started treating PLWHIV.

Because of the difference in location of these services, the participants from Kohtla-Järve and Jõhvi were not very concerned about people learning of their status while accessing care. The discreet entrance and separation of HIV and ART clinic from the central hospital, means that they rarely encountered any fear while accessing the clinic. On the other hand, the Narva participants are very nervous and hesitant about accessing care in the Narva hospital. The location of the HIV and ART clinic in the hospital is very open and any who enter risk either being identified as having HIV or being suspected of having HIV. As the participants shared, they know of many people who are terrified to access care in Narva for fear of their status being disclosed. The Linda Clinic does offer safer location and more positive atmosphere but access to services remains limited as an *infectionist* visits the clinic only once a week.

The numbers of registered ART cases in both regions help to clarify the differences in accessing care between the two communities. During data collection, February 2016 to March 2016, I was able to approach the three different clinics and obtain, at the time, updated numbers of registered ART recipients and of registered HIV cases. During the field study, the hospital in Kohtla-Järve had 1327 individuals registered as being HIV positive and 917 of those individuals were also registered at the ART clinic, which means that 69.1% of registered PLWHIV have visited the HIV and ART clinic and

have been registered into the ART program<sup>34</sup>. In Narva, the situation was very different. Although I was unable to obtain the exact number of cases from the Narva Hospital, through speaking with numerous health care professionals who work with ART and PLWHIV in the city, I learned that the Narva Hospital had between 500 and 600 PLWHIV registered as taking ART and the Linda Clinic had 140 registered. However, the healthcare providers I spoke with estimated that there were between 2000 and 2500 registered HIV cases in Narva. This means that only 25.6% to 37 % of registered HIV cases have accessed ART, which is substantially lower than the percentage of PLWHIV who have accessed ART in Kohtla-Järve and Jõhvi.

The participants who were also healthcare providers stated that there are some PLWHIV in Ida-Virumaa who travel to Tartu, Estonia's second largest city, to see an *infectionist* and access ART. When I asked them why PLWHIV would make the five-hour round bus trip to Tartu for treatment, they all answered that it was to maintain the confidentiality of their status. They were mostly individuals who either had no history of intravenous drug use or feared being identified as having HIV in Ida-Virumaa and had the means to travel. Moreover, unlike the clinics in Narva and Kohtla-Järve, they were not nervous of being seen at the Tartu hospital. Although I did not visit the location myself, my contacts in Ida-Virumaa informed me that the *infectionist's* clinic in the Tartu Hospital was not labeled as an HIV clinic but rather as a travel health clinic. Unlike the Narva or the Kohtla-Järve hospitals, an individual seeking treatment in the Tartu Hospital

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<sup>34</sup> These numbers only represent the percentage of known PLWHIV that have been registered into the state sponsored ART program, and should not be understood as a measurement of adherence to ART. From speaking to healthcare providers in the different communities, they estimate that only between 30% and 50% of people registered in the state sponsored ART program properly adhere to ART.

would not be identified as a person living with HIV, even by hospital staff, because the sign on the door was more generalized and not HIV or IDU specific.

The differences between Narva, Kohtla-Järve and Jõhvi highlight the influence of fear of disclosure on care-seeking behaviour. In Narva, where the risk of being identified is much greater, there are fewer people accessing ART than in Kohtla-Järve and Jõhvi. Moreover, that PLWHIV who have the economic means to travel to a different city prefer to access care outside of their own communities also highlights the risk of being identified and what it presents to PLWHIV. That an individual in Narva prefers to travel 3 to 5 hours, 4 to 6 times a year to Tartu or Tallinn to see an *infectionist* and obtain ART only further reveals the risks that becoming publicly identified as having HIV represents to the livelihood of PLWHIV in Ida-Virumaa.

### **A Poisoned Relationship: PLWHIV and Healthcare Providers.**

In addition to the fear of disclosure, this study also identified that healthcare providers act as a barrier to care and often discriminate against PLWHIV who seek services from them. In all of the interviews, discrimination by healthcare providers quickly emerged as why the participants are reluctant to access care, return for care or adhere to ART. Moreover, many of the participants explained their dissatisfaction and frustration in that some of the doctors they encountered knew less about HIV than they did, and that those doctors openly promoted measures to protect oneself from HIV based on the illness of HIV and not the disease of HIV. The combination of these two identified factors have not only resulted in the establishment of a very poisoned relationship with PLWHIV, but also reinforces the cultural metaphors of HIV stigma and enables structural discrimination.

The participants shared many stories, either regarding themselves or people they knew well, about experiences of discrimination by healthcare providers. These experiences ranged from a denial of services to being talked down to and acts of unprofessionalism that have had significant negative impacts on the lives of the participants. Nadia shared a difficult story about how she lost her husband, as she believes, because a doctor was unwilling to provide him the basic care and treatment he needed due to his HIV status. When asked for advice on how to live with HIV, Victor's family doctor shrugged his/her shoulders and told him, "do not get sick often." Natasha shared a story of when a nurse in a surgeon's office told her that no one would operate on her client because he was HIV positive. Olga was simply told to, "Go home and wait until you die." The frequency of these and similar experiences across both the interviews and during participant observation was so frequent that they cannot be seen as only individual cases between individual healthcare providers and specific patients. Instead, they imply the presence of a greater, widespread phenomenon in Ida-Virumaa; a phenomenon that many PLWHIV have encountered and one that a person living with HIV may never be able to avoid.

Discrimination by healthcare providers has been identified as a very problematic barrier to accessing care and ART adherence (Nyblade, Stangl, Weiss, & Ashburn, 2009, p. 12). The discriminative behaviour of healthcare providers identified in this study was similar to those identified in a study conducted in Tanzania: a series of different discriminatory and stigmatizing practices by healthcare providers towards PLWHIV including denial of care, neglecting or deferral of treatment for PLWHIV, verbally abusing the patient and disclosing patients' HIV status without their consent (Synergy,

2005, Nyblade et al., 2009). Similar discriminative behaviours were also identified in studies in Ireland (Surlis & Hyde, 2001), Nigeria (Adebajo, Bamgbala, & Oyediran, 2003; Reis et al., 2005), India (Khakha, 2003), Ethiopia (Nyblade et al., 2003), and the United States (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007). The impacts of discriminative behaviour by healthcare providers in this study, along with reluctance and fear of accessing care, unwilling to adhere to ART and traveling to different communities to access care, were also identified in the literature (Green & Platt, 1997; Kinsler et al., 2007; Nyblade et al., 2009; Surlis & Hyde, 2001). The similarities between this study's findings and those already established in the literature not only show that discriminative behaviour by healthcare providers towards PLWHIV is a global phenomenon, but also represents both a significant barrier to care and ART adherence for PLWHIV and presents a serious challenge to the efficacy of HIV interventions.

Although very limited, literature identifying HIV stigma, lack of knowledge and discriminative behaviour by healthcare providers has emerged in Estonia. Välimäki et al. (2008) conducted a study that compared the willingness of nurses to provide care to PLWHIV in three different countries: Finland, Lithuania, and Estonia. In this study, they identified that of the three countries the Estonian nurses were the least willing to provide care to PLWHIV. Although this study claimed that Estonian nurses held similar perspectives towards PLWHIV as those in Lithuania and Finland, they were the least willing to give bed baths, clean up faces of vomit, change bed linen, clean instruments, complete catheter care, or shave patients compared to the Lithuanian and Finnish counterparts (Välimäki et al., 2008, p. 591). Although this study did not clarify which Estonian city or region the participants were recruited in, the Estonian nurses'



unwillingness to provide services to PLWHIV reveals a possibly limited knowledge of HIV biology and transmission, and HIV stigma held towards PLWHIV was also identified in this study. It is also important to note that the 74% of the Estonian nurses in Välimäki et al.'s (2008) study were 35 years old or older, while only 26% were 34 years old or younger (592). This is very interesting because in 2010, Välimäki et al. conducted another study comparing the willingness of nursing and midwifery students to provide services for PLWHIV in Estonia, Finland, and Lithuania. This study identified that the majority of Estonian nursing and midwife students, 84% of whom were under the age of 24, were willing to provide the same services to PLWHIV asked of nurses in the Välimäki et al. (2008) study (Välimäki et al., 2010). Although the locations of the study in Estonia was not clarified, the difference in attitudes between the Estonian participants in these two studies supports the findings of this study that HIV stigma is primarily associated with people 25 years old and older, and that members of the younger generations are not as concerned with HIV as those of the older generations.

The exploratory nature of this study means that it is one of the first conducted that specifically examines HIV stigma and how it influences care-seeking behaviour of PLWHIV in Ida-Virumaa. However, the findings of this study coincide with the findings of others conducted in Eastern Europe and across the globe that have identified how HIV stigma and discrimination by healthcare providers also act as barriers to care. This provides an additional framework to examine how HIV stigma, discrimination and fear of discrimination in Ida-Virumaa not only act as barriers to care and ART adherence, but also support a system of structural discrimination against PLWHIV.

The behaviour of healthcare providers is thus promoting and empowering HIV stigma. By belittling and talking down to patients with HIV who come to see them, healthcare providers are conveying how they, and arguably society, view and understand PLWHIV. They are conveying to that individual that he or she is less than human and deviant, and such behaviour makes PLWHIV less willing to return for care.

Unprofessional behaviour in not providing accurate information to patients, only speaking to a patient through a door, or putting on additional gloves also conveys a sense of fear of PLWHIV and that they should not be associated with. Unprofessional behaviour also highlights the lack of knowledge of HIV biology held by healthcare professionals. Through their behaviour towards PLWHIV in Ida-Virumaa, healthcare professionals are not only reinforcing the symbolic relationship between the stigmatized PLWHIV, deviance and what is acceptable, they are also limiting PLWHIV's access to quality care. Healthcare providers are, therefore, producing and reproducing structural discrimination against PLWHIV, and members of at-risk populations.

### **Stigma and Structural Discrimination**

Social Control Theory argues that individuals, elites and the state use stigma to produce and reproduce social inequality and shape the social narrative of a country, and by doing so, are able to create symbolic markings between different categories of individuals and dictate the degree that stigmatized individuals are able to interact with the power structure of a society (Parker & Aggleton, 2003, pp. 17-18). In Ida-Virumaa, the powerful stigma associated with HIV is forcing PLWHIV to conceal their status out of fear of being identified as having HIV and the negative consequences that will result if their status becomes public knowledge. However, PLWHIV also strongly feel that they

are being discriminated against by healthcare professionals and by the state. One day, while discussing the newly implemented contractual agreement between PLWHIV and *infectionists*, Mrs. Antonova told me that the implementation of this policy was nothing but discrimination against PLWHIV. When I asked her why she thought it was discrimination, she angrily replied,

Because the contract is only for [PLWHIV]! They will not make a cancer patient sign such an agreement! A doctor will not tell a cancer patient that if he misses some doses of chemo the doctor will no longer give him chemo! They do not make people with tuberculosis sign it! They will not deny them DOTS. Who has to sign it? Only [PLWHIV]! It is discrimination!

Mrs. Antonova's resentment towards this new contract and statements from the participants portray the idea that HIV stigma is not only resulting in discrimination against PLWHIV, particularly by healthcare providers, but that HIV stigma has resulted in the structural discrimination of PLWHIV.

Link and Phelan (2001) describe structural discrimination as a situation when institutional practice and policies work to disadvantage stigmatized groups through the creation of a disabling environment that limits their ability to function in society, limiting their ability to access services that are already available to the non-deviant groups, and creating metaphors of fear and shame so that others will not interact with them (p. 372). This model effectively applies to PLWHIV in Ida-Virumaa. The participants not only identified the presence of powerful negative cultural metaphors and stigma associated with HIV and PLWHIV, but also that healthcare professionals hold and reinforce these stigmas by providing misinformation about HIV. The participants also expressed multiple instances when either they or people they knew were discriminated against by a healthcare professional when trying to access care. Through the lens of social control

theory these negative exchanges are reinforcing the negative stigma of PLWHIV and empowering the feeling of shame within PLWHIV, fostering the fear of HIV and PLWHIV, and reinforcing the paradigm of being deviant and being acceptable. That the participants in Narva are unwilling or refuse to visit the Narva Hospital to receive ART out of fear of being publicly identified also shows how stigma and discrimination influence a reluctance to access care. The use of withdrawing a disability pension and the new contract agreement between PLWHIV and *infectionists* to promote adherence also identify the structural level of this discrimination in that the discrimination is not only happening at the level between a doctor and patient but also between the Estonian Health Board and the PLWHIV community.

When examining structural discrimination and the influence of stigma on care-seeking behaviour of PLWHIV, it is important to analyze stigma in the historical, cultural, and political-economic context of Ida-Virumaa. The post-Soviet transitional period was a very difficult time for the people of Ida-Virumaa. Narva went from one of the most ideologically prosperous manufacturing communities in the Soviet Union to a city littered with abandoned factories, offices and apartment buildings. Kohtla-Järve went from a prosperous mining community to one with many closed and abandoned mines, chronic unemployment, and limited opportunities for those who either did not learn Estonian in their youth, or could not afford to pay for the expensive Estonian language courses.<sup>35</sup> Ida-Virumaa has consistently had the country's highest

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<sup>35</sup> Estonia's current minimum wage is €390 (\$576.90 CND) per month. Estonian language programs in Ida-Virumaa range between €400 and €640. By law, many Estonian companies are required to hire people who have at minimum an intermediate level of proficiency in Estonian. The necessity for being fluent in Estonian to find any employment higher than minimum wage, and that the cost of Estonian language program exceeds a month's salary, means that many ethnic Russians, particularly those in Ida-Virumaa, are structurally locked into their socio-economic status and with little social mobility. This has led to a lot of

unemployment rate and has seen substantially lower rates of government investment compared to Tallinn, Tartu and other predominantly ethnically Estonian populated communities.

Difficulties experienced by the country as a whole are more pronounced in Ida-Virumaa. The recent drop in GDP and recession has seen unemployment in Ida-Virumaa rise more than the other regions (Sarapik, 2016). Estonia's doctor crisis is also more pronounced in Ida-Virumaa. For years Estonia has been struggling to retain its newly trained doctors in Estonia, as many move to Finland or other EU countries that offer higher wages. Ida-Virumaa is facing a systemic shortage of doctors and *infectionists* (Klada, 2016; Leinucs, 2016). Because Ida-Virumaa is often associated as being a very dangerous place for Estonians, convincing young doctors to move to Ida-Virumaa is a very challenging endeavor, as the Estonian government already struggles to retain newly trained doctors in Tallinn and Tartu. Moreover, as the majority of Ida-Virumaa's doctors were trained during the Soviet Union, many of them are approaching retirement age with few doctors available to replace them (Klada, 2016).

Much of Ida-Virumaa's current social, political and economic marginalization is a result of ethnic-nationalist policies implemented during the early 1990s as the newly independent Estonian government sought to both establish Estonia's newly won independence from the Soviet Union and ensure Estonians would remain masters of their own house; however, these policies also resulted in the political-economic marginalization of Estonia's ethnic Russian minority (Berg, 2002; Bouchard, 2003; Černov & Kisseljova, 1995; Lauristin, 2003; Lauristin & Vihalemm, 2009; Raun, 1995;

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frustration and a sense of hopelessness among ethnic Russians that were regularly encountered during participant observation.

Toivo U. Raun, 2001; Raun, 2003; Saar & Aimre, 2013; Siiner, 2011; Smith, 1998; Vihalemm & Masso, 2003). Although in recent years the Estonian government has identified the consequences of marginalization and has undertaken steps to bridge the ethnic conflict between the Estonians and ethnic Russians, particularly among youth, the effects of this marginalization are still clearly visible when one travels the ten kilometers from the multiple new shopping centers of Jõhvi, which has a relatively large Estonian population, to the abandoned Soviet-era buildings of Kohtla-Järve.

Within this socioeconomic context of PLWHIV and intravenous drug users living in Ida-Virumaa, it is possible to understand how structural discrimination influences their lives. PLWHIV in Ida-Virumaa represent a marginalized community within a marginalized population in a marginalized region of Estonia. In Ida-Virumaa, PLWHIV and IDUs perceive that they are seen as less than human, amoral and that they should not be associated with. Ida-Virumaa is predominantly populated by ethnic Russians and continuously had Estonia's highest unemployment rates since 1991 (Tammaru & Marksoo, 2011, p. 228). The majority of PLWHIV and IDUs in Estonia are members of the ethnic Russian minority, who have been politically, economically, and socially marginalized in Estonia to the point that, even if they were born in Estonia, they only qualify for Estonian citizenship if they pass an Estonian language exam (Saar & Aimre, 2013; Siiner, 2011; Zabrodskaia, 2009). Most PLWHIV and IDUs in Ida-Virumaa are ethnic Russians who grew up in the Soviet Union, never learned Estonian at school, and cannot afford to take Estonian language classes. The lack of Estonian proficiency combined with low-education and/or no professional training and a past history of intravenous drug uses means that securing any employment is very challenging. Due to

the political and economic marginalization, it should not be surprising that the average unemployment rates for ethnic Russians between 1990 and 2010 were 23% compared to 13% for ethnic Estonians (Tammaru & Marksoo, 2011, p. 227).

To the participants of this study, PLWHIV are stigmatized and marginalized in the ethnic Russian minority. They also strongly feel that the Estonian majority politically, economically, and socially marginalizes ethnic Russians, particularly those who were either born in Estonia or moved to Estonia during the Soviet era. Ida-Virumaa has the country's highest unemployment rates and lowest GDP growth. PLWHIV in Ida-Virumaa are therefore not only stigmatized for having HIV but also for being IDUs, being ethnically Russian, and being from Ida-Virumaa.

The stacked stigmas associated with PLWHIV and structural discrimination make life in Ida-Virumaa very difficult for people like Olga. She is like most PLWHIV in Ida-Virumaa, who are ethnic Russians and are either active intravenous drug users or have a history of intravenous drug use. If a person who is living with HIV were to give up intravenous drug use, they might face many difficulties trying to emerge into society. First of all, there are very few job opportunities for people in Ida-Virumaa and even fewer for those who either do not speak Estonian and/or have little education or vocational training. Moreover, if an individual is publicly known to have a history of intravenous drug use, it may be nearly impossible for him or her to find employment in their communities, so he or she has to travel to other towns or cities for irregular seasonal employment, as was the situation for Peter and Constantine. That individual must then forever be conscious of the risk that if anybody learned about his or her HIV-positive status, he or she could risk losing employment and be socially ostracized in the

community, making finding future employment extremely difficult. In addition, there would be the possibility that every time he or she sought treatment from a healthcare provider, the healthcare provider could belittle, insult or simply deny access to services. Essentially, these barriers, lack of opportunity and structural discrimination limit the ways PLWHIV and IDUs in Ida-Virumaa are able to function in Estonian society.

The conceptual framework of stigma as a form of social control does have its criticisms and limitations. Deacon et.al (2005) argue that by emphasizing the role of the state and/or institution, social control theory overlooks the importance of individual agency of people with and without the stigma (p. 17). They argue that social control theory emphasizes a linear causal relationship between stigma, discrimination, and social inequalities. They also argue that stigma does not always follow traditional inequality fault lines within a society and that stigma can act as a platform for social activism (Deacon, 2005, p. 17). Moreover, they see stigma through the lens of the blaming model where stigma acts as an emotional response to separate oneself from possible harm (Deacon, 2005, p. 17).

The blaming model of stigma does have its relevance in providing a framework to understand how individuals perceive and reinforce HIV stigma through their daily lives. However, the blaming model does not provide an effective means to understand how HIV stigma is reinforced and produced at the individual and the elite and state levels in Estonia. The social control theory, however, does provide a framework that is valid in understanding HIV stigma in Ida-Virumaa because the examination of the perspectives and effects of HIV stigma in Ida-Virumaa cannot be accurately done without understanding the greater ethnic, historical and political-economic context of present and



past Estonian government policy. Nor does the blaming model provide a means to understand the reinforcement of HIV stigma in relationship to the ethnic conflict between Estonians and ethnic Russians, and how this conflict and government policies have marginalized the ethnic Russians of Ida-Virumaa. Although Deacon et al. argue that stigma can result in social activism, activism in Ida-Virumaa contains serious risks for PLWHIV as openly promoting one's status can result in serious negative consequences. Moreover, the structural discrimination against PLWHIV is not only at the local level by their doctors, but also at the state level through the implementation of policies specifically designed to target or disadvantage PLWHIV.

The recently implemented patient-*infectionist* contract provides a solid example of structural discrimination against PLWHIV. Although this agreement was implemented as a way to encourage or force ART adherence<sup>36</sup>, it is essentially a tool of the state telling PLWHIV that if they do not comply and take ART, they will have to buy their own medications. Unfortunately, as very few PLWHIV in Ida-Virumaa are able to pay more than €5000 for this treatment, and by threatening to remove people from ART for non-adherence, *infectionists* are informing patients that they are willing to condemn them to death. Although the decision to remove an individual from the state funded ART program for non-adherence is based on the volition of individual *infectionists*, there is always a chance that a person could be permanently removed from and have no access to ART.

In addition to the new contract, the threat of removing the disability pensions to

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<sup>36</sup> During data collection and analysis, this study was able to identify many factors for why PLWHIV are unwilling to adhere to ART. The reasons for non-adherence identified are closely related to the findings of this thesis. However, the findings of this study related to non-adherence are not included because they go beyond the requirements of a Master's Level Thesis. These findings will be published in the future and a report describing the findings will also be sent to the EHPV, and, with the EHPV's permission, to the Estonian Institute for Health Development.

force adherence is also a means of structural discrimination. Although deeply flawed for rewarding non-adherence, the disability pension available to PLWHIV represents the only stable income for many PLWHIV in Ida-Virumaa, where employment opportunities are very limited. Yet *infectionists* often use the threat of denying an individual his or her pension if they do not adhere to ART to encourage adherence. This creates a very perplexing situation for PLWHIV who live with this pension because they need to refrain from ART to continue receiving the pensions. *Infectionists* threaten to remove the pension if they do not adhere, and if they do successfully adhere to ART and their health status improves, they will be stripped of the pension with limited other opportunities available to replace that lost income.

The combination of these two policies by *infectionists* and the state are actually pushing PLWHIV further away from healthcare providers. PLWHIV already face difficulties accessing care and ART, but now the state is forcing them to adhere to ART by threatening to limit a person's access to an important state subsidy and ART. By forcing PLWHIV to adhere to ART via threats of removing benefits, the Estonian government is only pushing PLWHIV further away from care and healthcare providers when it needs to be bringing them into care.

Unfortunately, this situation looks like it may become even more difficult for PLWHIV. On February 1<sup>st</sup> 2016, the Estonian government started exploring the possibility of reducing *infectionist* services in Ida-Virumaa by closing the Infection Clinic in the Narva Hospital due to budget constraints (Smirnov, 2016). If the Estonian government goes ahead with this proposal, it will not only close the last remaining fulltime *infectionist* clinic in the city, but will also be forcing PLWHIV in Narva to travel

over an hour to Jõhvi<sup>37</sup>, multiple times a year, to access ART. This means that a person living with HIV, who is already socially-economically marginalized, needs to buy two intercity bus tickets and two municipal bus tickets and spend the entire day travelling in order to access care. People living on the state pension cannot afford this, and PLWHIV who are employed and can afford it risk being identified because they need to frequently travel between Narva and Kohtla-Järve; questions will be raised at work and in the community as to why they have to leave work so often to go to Kohtla-Järve. If this policy is implemented, Narva will not have a full time *infectionist* to look after the more than 2000 cases of PLWHIV. As the *infectionist* in the Narva Hospital's infectious disease clinic is already extremely overworked, the implementation of this policy would only result in yet another barrier limiting PLWHIV's access to ART. More specifically, this policy would limit the ability of ethnic Russians living with HIV to access care.

These state policies combined with frequent discrimination by healthcare providers have created a poisoned relationship between PLWHIV and healthcare providers. Many PLWHIV in Ida-Virumaa have lost their faith in healthcare providers and in the state. Although these sentiments do not apply to all healthcare providers in Ida-Virumaa, the participants in this study hold serious reservations towards the sincerity and competence of family doctors, *infectionists*, social workers, and other healthcare providers. Intentional disclosure of an individual's HIV status to the public by a social worker, unprofessional behaviour by doctors, and a feeling that PLWHIV are second-grade, have resulted in this growing lack of faith in the healthcare system. These discriminative and unprofessional behaviours by healthcare providers not only reinforce

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<sup>37</sup> Although the ART clinic for Kohtla-Järve and Jõhvi is located in the Akhtmae village of Kohtla-Järve, the bus depot in Jõhvi is much closer to Akhtmae than the bus depot in Kohtla-Järve. Although other routes are available, many people commonly travel through Jõhvi when traveling from Kohtla-Järve to Akhtmae.

HIV stigma, but also push PLWHIV further away from care, making them less likely to access it in the future.

PLWHIV in Ida-Virumaa have lost much trust in their healthcare professionals and the government, and this presents substantial problems for the efficacy of public health interventions and adherence to ART. PLWHIV, even those who work with healthcare providers, such as Natasha and Nadia, do not openly trust healthcare providers because of fear, past experiences of discrimination, a sense of doctors' incompetence, and the possibility that meeting a healthcare professional could result in severe social, economic, psychological harm, and, in the case of Natasha and the surgeon, maybe even death. In this tense relationship, it is only understandable that PLWHIV mistrust ART. The severe side-effects that are commonly associated with ART make taking ART very difficult for PLWHIV, particularly for IDUs, because many PLHIV not only have to cope with these side-effects, but also have a poor understanding of ART and Western pharmacology and simply do not understand why it is necessary<sup>38</sup>. Instead of trying to explain ART in a way IDUs and PLWHIV can understand, *infectionists* and the Estonian government have tried to strong-arm them into adherence, which has resulted in them becoming even more mistrustful of and angry with the government and healthcare providers.

### **Limitation**

Although this ethnographic study was able to successfully document HIV stigma and identify how HIV stigma influences care-seeking behaviour, it is not without its

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<sup>38</sup> The factors for non-adherence to ART in Ida-Virumaa identified in this study include poor understanding of ART, cultural perspectives of health and pharmacology, side-effects, cultural understandings of HIV, difficulties accessing ART, not trusting healthcare providers, and the loss of the disability pension.

limitations. The first limitation is that the time in the field was limited to eight weeks spent in three different communities. This limited amount of time means that the perspectives expressed in the study are based on the perceptions held by PLWHIV, the healthcare providers who were willing to speak with me, and employees and volunteers of the EHPV. Unfortunately, the time spent in each location was not enough to develop strong relationships with local residents, who were not directly associated with the EHPV, so that they would openly speak with me about this topic. As a result, the findings of this study are based on the experiences of the stigmatized and those who help the stigmatized, and do not include perspectives directly from members of the general population.

There are also some issues regarding the sample of this study. The time constraints of data collection combined with not being from the region meant that participants for the semi-structured interview were recruited with the aid of the EHPV. Although the EHPV does have many members and individuals who access their services, the participants recruited represent a group of individuals who trust the EHPV, where confident with their HIV status, and were willing to speak with a foreign researcher about their experiences. The sample of participants thus reflects a convenient sample of individuals who accessed the EHPV and were willing to participate in the study, and because few prospective participants were willing to participate, a random selection of participants was not possible. Nevertheless, as PLWHIV in Ida-Virumaa are a marginalized, vulnerable population, this approach was still acceptable for the purpose of this exploratory study.

Further, the participants of this study are all ethnic Russian and thus expressed the perspectives held by the ethnic Russians. This study sought to include ethnic Estonian PLWHIV to participate in the study, but no prospective Estonian participants were willing to participate in the study. The semi-structured interview sample also mostly contained individuals who either are intravenous drug users or have a history of intravenous drug use. Only two of the participants who were living with HIV had a history of high-risk activity such as drug use, commercial sex work, unprotected sex or promiscuous lifestyles. Efforts were made to include other high-risk populations into the study, particularly commercial sex workers and MSM, but none approached by the EHPV were willing to participate in the study. One commercial sex worker, who was interested in participating, disappeared from the EHPV and could not be reached to arrange an interview.

The findings of this study only portray the experiences and perspectives of PLWHIV and healthcare providers who have a positive relationship with PLWHIV, and not the perspectives held by family doctors or *infectionists*. Although efforts were made in the field to recruit doctors to participate in the study, no doctors were able to participate due to schedule conflicts. I was, however, able to meet with a few doctors while in the field, and although they provided me with interesting information regarding HIV and the population health in Ida-Virumaa, none of them was able to participate in the study.

The healthcare providers who participated in the unstructured interviews were all introduced to me through the EHPV. They were individuals who were very compassionate for the difficulties faced by PLWHIV and were frustrated with how other

healthcare providers treated PLWHIV. As recruiting healthcare providers was a very difficult task in the field, those who participated reflect a convenient sample because they were the only ones encountered who were willing to be interviewed.

The final limitation of this study is that I was an outsider to the community. As I was not from Ida-Virumaa, not ethnic Russian, not Estonian, do not have a history of intravenous drug use, am not HIV positive and speak Russian as a second language, it is very difficult to accurately relate myself to the experiences and perspectives of the participants. Nevertheless, the results in this study are presented in the words of the participants supported by an understanding of Russian culture honed through years of experience living in different Russian communities. All efforts were undertaken to ensure that the findings presented in this study accurately reflect the emic perspectives of the participants.

## Chapter 6: Conclusion

This study explored the cultural perspectives, metaphors and stigmas of HIV that are held and experienced by people living with HIV in Ida-Virumaa, Estonia. The purpose of this study was to document the contemporary cultural metaphors and stigmas of HIV, and to explore if and how they act as a barrier to care and ART adherence for PLWHIV. The findings not only identified clear cultural metaphors and stigma of HIV and PLWHIV, but also that fear of disclosure of status and discrimination from healthcare providers represent significant barriers to care for PLWHIV. The findings also indicate that the combination of HIV stigma, fear of disclosure, discrimination from healthcare providers and certain state policies have fostered an environment of structural discrimination that not only limits PLWHIV in Ida-Virumaa, but also pushes them away from the healthcare system.

The research methods used were participant observation, semi-structured interviews with PLWHIV, and unstructured interviews with healthcare providers who work with PLWHIV. Ethnography was the methodology utilized to obtain the emic perspectives of how PLWHIV and those who work alongside PLWHIV understand HIV stigma, the challenges of living with HIV in Ida-Virumaa, the difficulties experienced by PLWHIV when accessing care, and the reasons why they often refuse to access care.

The study was able to identify two distinct theme clusters identifying the HIV stigma and the cultural perspectives of HIV/AIDS and PLWHIV. The cultural metaphors of HIV describe it as an illness that causes a rapid death, is untreatable, is a disease of *narkomani*, and is *microbii* that can be transmitted from one person to another through either direct contact with and or being in close proximity to a person living with HIV. In



addition to this cultural metaphor of HIV, a clear metaphor of a person living with HIV also emerged from the data. To the general population of Ida-Virumaa a person living with HIV is: a *narkoman*, less than human, deviant, not worthy of society, and is solely responsible for his or her HIV status.

The study also clearly identified that the symbolic meaning of HIV and PLWHIV often results in the discrimination of PLWHIV, that can include verbal, emotional, psychological, and or physical abuse, as well as result in severe social and economic consequences for PLWHIV and their families. Because of the very serious problems that can arise if someone is identified as or even suspected as being HIV positive, PLWHIV are very secretive about their status. This makes accessing care for them a very risky endeavor. If there is a chance that a individual's HIV status could be disclosed when accessing care, that individual might either go to great lengths to obtain care from another community, or may simply avoid accessing care. How care facilities for PLWHIV are established also represent an important factor of whether or not a person living with HIV will access that location for care. This was clearly evident in the comparisons of the percentages of PLWHIV access care in Narva compared to those accessing care in Kohtla-Järve and Jõhvi.

Finally, this study also identified that PLWHIV frequently experience unprofessional and discriminative behaviour from healthcare professional when they do access care. The behaviours of healthcare professionals identified by the participants that make them unwilling to access care include: being talked down to, unprofessional behaviour and discrimination, unwillingness to provide adequate services for PLWHIV, and a lack of knowledge of HIV biology and treatment. Moreover, some doctors in Ida-

Virumaa have and continue to openly promote negative perspectives of PLWHIV and HIV. The powerful symbolic meaning associated with HIV stigma seriously undermines efforts to control the epidemic, as many PLWHIV are either reluctant or terrified to access services out of fear of being identified by community members or that a healthcare professional would spread news of an individual's HIV-status throughout the community. Consequently these behaviours have resulted in a poisoned relationship where PLWHIV have not only lost trust in their healthcare providers, but also often feel that healthcare providers no longer care about them. This has resulted in a growing fear of healthcare providers, and that receiving help from a doctor could result in serious health consequences for a person living with HIV, including his or her death.

This exploratory study will contribute to the literature of HIV research and ART adherence in Estonia by providing a comprehensive framework of how shared cultural perspective of HIV, PLWHIV and HIV stigma in Ida-Virumaa County, which has one of the Estonia's highest HIV incidence and prevalence rates, and how these perspectives act as barriers to care and ART adherence. The findings of this study also offers valuable insight into why PLWHIV are unwilling to access care, adhere to ART, or listen to healthcare providers, which presents a serious challenge to controlling the HIV epidemic in Ida-Virumaa. Issues of fear of disclosure and discrimination from healthcare providers present very serious challenges not only for PLWHIV, but also for the efficacy of HIV intervention programs.

This study did have a few limitations. First, the participants were all members of Estonian's Ethnic Russian minority. This means that the perspectives expressed reflect only those of ethnic Russians and not ethnic Estonians. Future research will need to be

conducted to compare and contrast the perspective of HIV held by ethnic Estonians and ethnic Russians, and examine if the barriers to care are similar or different for members of each ethnic group. The second limitation was that all perspectives shared in this study are only those of PLWHIV and some healthcare providers who work along side PLWHIV. Unfortunately, not one doctor or *infectionist* was able or willing to participate in the study despite efforts made to recruit them. This means that the perspectives and inferences expressed by the participants related to discrimination from healthcare providers only represent the perspectives PLWHIV and those who work closely with PLWHIV.

## **Recommendations**

This exploratory ethnographic study was the first study conducted in Ida-Virumaa that sought to examine and document the perspectives of stigma held by the people of Ida-Virumaa and how stigma influences care-seeking behaviour. Although the findings of this study identified how HIV stigma acts as a barrier to care, more research needs to be conducted to examine these results. More research needs to be done to understand how perspectives of HIV are held and promoted throughout the general population and within social collectives to identify how HIV stigma is promoted and to devise a means to counter the spread of HIV stigma.

Future research must also examine the beliefs and perspectives of ART held PLWHIV that influences their reluctance or unwillingness to adhere to ART. Although this study was clearly able to identify how HIV stigma, discrimination, and fear of discrimination influences access to care and ART adherence, more research needs to be conducted to understand additional reasons as to why PLWHIV are unwilling to adhere

to ART. Although registration of PLWHIV in the ART programs of Kohtla-Järve and Jõhvi are high, estimated adherence rates remain very low and are estimated to be even lower in Narva. More research is needed to understand the emic reasons as to why many PLWHIV do not want to adhere to ART, so that new and or revised programs maybe implemented to effectively increase adherence.

This study and the literature clear identify how fear of disclosure and the consequences of being identified as having HIV present a serious challenge PLWHIV. The location of HIV related service plays a very important role in the decision making process of PLWHIV who are trying to access care. This study identified that many participants will travel to other cities to access care out of fear of being identified as having HIV. The findings also indicated that many participants were unwilling to access care if they felt that were at risk of being identified, particularly those who receive or had received treatment from the Narva Hospital. As accessing care and ART adherence is a significant challenge in Estonia's efforts to control HIV, comparison research needs to be done throughout the country to identify the type of centers participants feel safe accessing, then these types of centers need to be implemented. The implementation of safe services to access to HIV related care, would greatly aid individual's living with HIV's willingness to access care more regularly, particularly in Narva.

This study also clearly identified that discrimination and unprofessional behaviour from healthcare providers represent a significant barrier to care for PLWHIV in Ida-Virumaa. The effects of the discrimination on care-seeking behaviour and ART adherence identified in this study are supported by the literature, and present a serious challenge to the efficacy of HIV interventions. More research must be conducted in this

area to identify both the patient and healthcare providers'emic perspectives of HIV, PLWHIV, and discrimination, so that effective interventions designed to address the discrimination of PLWHIV when they are accessing care. Such interventions would go along way in not only increasing access to care and ART adherence, but would also aid in repairing the current poisoned relationship between healthcare providers and PLWHIV.

Finally, efforts must be made by government policy and healthcare providers to reset the relationship between them and PLWHIV. In Ida-Virumaa, PLWHIV have already experienced years of marginalization and discrimination by government policies and healthcare providers. The years of discriminative behaviour and policies have resulted in making PLWHIV both resentful of healthcare providers and hesitant to approach them for care. The trust between patient and doctor has been lost, and many patients feel that their healthcare providers not only know nothing about HIV, but also do not care about what will happen to them. This relationship needs to change. Future programs and interventions must ensure that steps will be taken to invite marginalized PLWHIV into the programs and that nothing happens to further push them away. If healthcare providers and policy makers do not take steps to change this poisoned relationship, PLWHIV will only be further marginalized and pushed away from care, which will ultimately undermine any efforts undertaken to address HIV in Estonia.

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## **Appendix I**

### **Interview Guide: Semi-structured Interviews**

#### **Prior to Beginning the Interview<sup>39</sup>**

- Greet the participant
- Go over informed consent and explain the purpose of the study
- Begin tape-recording

#### **Experience Living with HIV**

- 1) Before we begin, would you please tell me a little bit about yourself? I am interested in learning about who you are.
  - a) Where are you from?
  - b) Where did you grow up?
  - c) What are your interests?
  - d) What have you been doing for the past few years?
- 2) Do you have any questions you would like to ask me before we begin?
- 3) What I would like you to do now is tell me about your experience of living with HIV. You can begin wherever you like and include or leave out whatever you choose. I am interested in finding out about your experience. Could you please tell me about this?
  - a) How did you feel when you learned that you had tested positive for HIV?
  - b) What were your thoughts for the first few days after you learned about your diagnosis?
  - c) When you learned that you had HIV, how did you think you contracted HIV? Have your thoughts of how you became HIV positive changed overtime?
  - d) How would you say your life has changed since you were diagnosed with HIV?
  - e) Has your relationship with your family changed since you learned that you were HIV positive?
  - f) How about your relationships with your friends or people you know in the community?
- 4) What would you say are the most difficult aspects living with HIV?

#### **Internalized HIV Stigma**

- 1) What I would like you to do now is explain to me what does HIV mean in [informant's city of residence] and what does it mean to have HIV in [informant's city of residence]?

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<sup>39</sup> Numbered italicized questions represent interview questions, while letters and roman numerals represent prompts and probes.

- 2) Through your own experience, would you please explain to me how the people of [informant's city of residence] view or understand HIV and people who live with HIV?
- 3) In your experience, please explain to me how these perceptions affected you or people you know?
  - b) What about in the community?
  - c) What about at care centers?
- 1) Do you feel or think there is a difference in how people view or treat people who live with HIV compared to people who use drugs?
  - a) Could you explain to me how these perceptions influence your willingness to disclose (inform) to others that you have HIV?
  - b) Are there people or groups who you are more willing to disclose to? Why?
    - i) Are there people or groups who you are less willing or refuse to disclose to? Who are they and why?
- 2) In your experience, are there some groups of people in [informant's city of residence] who are more accepting of people who live with HIV?
  - a) Who are they?
  - b) Could you explain to me how they are more accepting? How are they different from the other groups?
  - c) Would you please tell me about your experience with members or facilities of this/these groups?
- 4) Are there some groups that are less accepting or hostile towards people who live with HIV?
  - a) Could you tell me your experiences with this/these groups?
  - b) Why do you think they are less accepting or hostile towards you?
- 5) Do you think ethnic Russians in Estonia understand HIV different than Estonians?
  - a) Do you think that ethnic Russians understand HIV different than those in Russia?
- 6) The final questions I would like to ask you regarding this topic are about how different groups of people view HIV.
  - a) In your experience, how do health care providers view and/or treat people living with HIV?
    - (1) Are their views different from the people of [informant's city of residence]? How so?
  - b) How do you think Estonians, not living in [informant's city of residence], view or understand people who live with HIV?
    - (2) How about the Estonian government?
  - c) Finally, how do, in your experience, the people of Russia or the Russian government view and understand HIV and people living with HIV?
- 7) What should other people know about HIV and people living with HIV?

## Care-seeking Behaviour

- 1) For the final section of this interview, I would like you to tell me about your experience in accessing care? Please begin anywhere you like, but I would like to know about your experience in accessing and receiving care for HIV?
  - a) What forms of care have you accessed or tried to access?
    - i) Are you still using this form of care? How long did you access this care? (If so) why did you stop?
- 2) In your experience, have you ever been hesitant or reluctant to access care? Could you please explain to me what has prevented you from seeking care?
  - a) Were you able to navigate this/these difficulties to access care?
  - b) How did you do so?
- 3) What I would like you to do now is explain to me your experience with antiretroviral therapy. Please begin by telling me what you know about antiretroviral therapy, and then tell me what you think about it and your experience with it?
  - a) Has your doctor ever prescribed anti-retroviral therapy to you?
    - i) When were you prescribed ART?
    - ii) How long did you take ART, and are you still taking ART?
    - iii) If I may ask, over the past 3 days, how many doses did you miss?
      - (1) Would you please tell me why you missed these doses?
- 4) Please explain to me the concerns you have about ART, if you have any?
- 5) In your experience, how do the people of [informant's city of residence] view or understand antiretroviral therapy? What are the views people have about those who use ART?
- 6) What is the biggest barrier to accessing ART?
  - a) Do these experiences, fears, or concerns influence you, or others you know, to follow ART as your doctor prescribed?

## Additional Topics

Support from Family

Support from community groups

Perspectives of Health Care providers

## Final Question

*Is there anything I have not asked you about that I should have?*

## **Appendix II**

### **Interview Guide: Unstructured Interviews**

#### **Introductions**

- Greet and thank the participant.
  - Go over informed consent and purpose of the study.
  - Begin recording
- 1) Before we begin, could you please tell me a little bit about yourself? I am interested in learning about who you are.
    - a) Where are you from?
    - b) Where did you grow up?
    - c) What are your interests?
    - d) What have you been doing for the past few years?
  - 2) Do you have any questions you would like to ask me before we begin?
  - 3) How has life been in [informant's city of residence] been recently? Have you noticed any changes, and what do you think about these changes?
  - 4) What can you tell me about the organization you work for/are a part of? How long have you been apart of the organization?

#### **Perceptions of HIV and People living with HIV/AIDS**

- 1) To begin, would you please tell me what you know about HIV?
  - a) What do you know about the HIV epidemic in [informant's city of residence] and Ida Virumaa?
    - i) In Estonia?
    - ii) In Russia?
- 2) How and or why do you think people are contracting HIV in [informant's city of residence]?
- 3) What I would like you to do now is explain to me what does HIV mean in [informant's city of residence] and what does it mean to have HIV in [informant's city of residence]?
- 4) Through your own experience, would you please explain to me how people of [informant's city of residence] view or understand HIV and people who live with HIV?
  - a) Do you feel there is a difference in how people in [informant's city of residence] view or treat people who live with HIV compared to people who use drugs?

- b) How do you think Estonians view people who live HIV?
    - i) How about the Estonian Government?
    - ii) How about Russian's living in Russia, how do you think they view HIV and people who live with HIV?
  - c) Why do you think people who have HIV may try to hide their diagnosis?
- 5) How do you perceive HIV, and people who live with HIV?
  - a) Who do you perceive as members of at risk populations?
    - i) How do you perceive these populations?
  - b) How do you think people at your organization and your friends view HIV, people who live with HIV and at risk populations?
- 6) Why do you think that most of the people living with HIV in Estonia are Russian-speakers?
  - a) What do you think needs to be done to lower the number of new HIV cases among Russian-speakers?
  - b) What do you think people who are HIV positive should do to manage their disease?
- 7) The Estonian government is currently offering many programs for intravenous drug users and people who live with HIV to combat the HIV epidemic. What do you know of these programs?
  - a) Could you please explain to me your opinion about these programs?
    - i) Needle Exchanges
    - ii) Methadone replacement therapy
  - b) Do you think that people with HIV or IDUs use these services?
- 8) What do you know about anti-retroviral therapy?
- 9) The Estonian government currently offers anti-retroviral therapy at no cost to people who are living with HIV/AIDS. Could you please explain to me how you feel about this program?
  - a) Are there any reasons that you can think of as to why people living with HIV would not use ART?

## Appendix III

### Project Description and Informed Consent for Semi-Structured Interviews

#### I. Study Team

##### **Student Researcher/Principal Investigator:**

Tyler Wood, Graduate Student, Interdisciplinary Department (Anthropology/Health and Human Science) University of Northern British Columbia (UNBC), Canada

Phone Number:

Email Address: [twood@unbc.ca](mailto:twood@unbc.ca)

##### **Research Assistant**

*Name*

Phone Number:

Email Address:

##### **Research Assistant**

*Name*

Phone Number:

Email Address:

#### II. Sponsor

This study funded through research awards provided by the University of Northern British Columbia (UNBC). As this study is funded through internal grants of the UNBC, there are no potential conflicts of interest between the researcher and UNBC.

This study is being conducted in partnership with the Estonian Network of People Living with HIV (EHPV), and the EHPV are the main beneficiaries of this research project. The Estonian Network of People Living with HIV is a non-government, non-profit organization that seeks to better the lives of people living with HIV/AIDS and members of at-risk populations in Estonia and works reduce the number of new HIV infections in the country. If you would like to learn more about the EHPV and the services they provide please ask a member of the research team to provide you with brochure or you can visit their website at [ehpv.ee](http://ehpv.ee).

#### I. Purpose of Study

This study, Perspectives of the Influence of Stigma on Access to Antiretroviral Therapy among Russian-speakers living with HIV/AIDS, is part of a graduate thesis being undertaken by Tyler Wood at UNBC. This study has two objectives:

- 1) To identify and document HIV stigma held by Russian-speakers in Ida-Virumaa, Estonia.
- 2) To explore how HIV stigma influences care-seeking behaviour and access to antiretroviral therapy.

We are inviting people like you, who are Russian-speakers in Ida-Virumaa, to help us understand your experience with HIV stigma and how it influences or impacts your life. Participation in this study is entirely voluntary, and you are free to withdraw from this study at any time. You are also free not to answer any questions that make you feel uncomfortable. If you choose to withdraw from this study, any information you provided up to this point will also be withdrawn from the study and securely destroyed.

If you agree to participate in this study, we will:

- 1) Give you a short form with some questions to complete.
- 2) You will then participate in a sixty to ninety minute interview with the researcher and a research assistant.
- 3) The interview will be audio recorded and transcribed at a later date.

## **II. Potential Risks of the Study**

We do not think there is anything in this study that could physically harm you. However, some of the questions we ask may seem sensitive or personal, and might upset you. You do not have to answer any questions if you do not want to.

Although we will understand the importance of protecting your anonymity and will do everything possible to secure both your identity and the information you provide, there is the potential risk that information about you that could harm you could be divulged. This divulgence of information might result in serious consequences for you socially (friends, family, relationships) and professionally (work).

At any point in the study, if you reveal that there has been an incident that involves a crime or the physical abuse and/or the neglect of the child (or that there is a risk of such occurring) please be advised that the research must, by according to Estonian law, report this information to the appropriate authorities. There is also a remote possibility that the Estonian Police may officially request or seize a copy of the data or the transcripts. If this does occur, the research team is required, by law, to handover the interview recordings and transcripts to the police.

If at any point in the study, you feel uncomfortable or upset and wish to end your participation, please inform the researcher or research assistant immediately and your wishes will be respected.

Do you understand the potential risks of this study?

☐ Yes

☐ No

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



### **III. Potential Benefit of the Study**

One of the potential benefits of this study is that you will be able to share your perspectives and experiences with someone who will listen to all you have to say and not judge or belittle you in anyway.

The experiences and perspectives you share with this study may have a positive influence on the change of both public perspectives and understandings of HIV and help other living with HIV overcome fear and access antiretroviral therapy.

Others may also benefit from what we learn in this study as the findings could result increasing the accessibility and efficiency of programs, including antiretroviral therapy, designed to increase the quality of life for people living with HIV in Ida-Virumaa.

### **IV. Services:**

The Estonian Network of People Who Live with HIV (EHPV), provide many services to people living with HIV/AIDS and members of at-risk populations. These services include: psychological counseling, individual and group counseling, peer counseling, family counseling and support services for children, free condoms, access to social workers and HIV testing.

If you would like to access these services either as a result of this of participating in this research or for other reasons, please inform the principle research or research assistant and he or she will help you make the necessary arrangements with the EHPV.

### **V. Anonymity and Confidentiality**

Your anonymity will be respected. Information that discloses your identity will not be released without your consent. All electronic and physical documents related to you will be kept in secure location for the duration of the study. You and other participants will not be directly identified in the research records, or in any reports or publication of the completed study. In place of your name, you will be assigned a pseudonym either of your or the researcher's choosing. If you are worried that your position in a specific community would disclose your identity, inform us and we will not disclose the community where you are from. All data and information collected during this study will be stored in a secure location for 4 years. Digital copies of the data will be kept on a secured, password protected external hard drive, and any paper records will be securely stored in a locked office until they are digitally recorded, and then they will be destroyed. After 4 years, the information will then be securely destroyed through the shredding of paper and the deletion of digital files.

Access to the raw data of this study will be highly controlled. Those who will have access include Dr. Michel Bouchard of the UNBC, and Dr. Josée Lavoie of the University of Manitoba. A research assistant, a transcriber and a translator will also be hired to aid in

the study, and will be required to sign a confidentiality agreement prior to accessing any hard data.

All efforts will be undertaken to protect your confidentiality and anonymity. However, due to the small study size and that a person you know may have referred you to us your total anonymity cannot be guaranteed. However any information you chose to share with us during this interview will not be shared with other participants or with individuals outside of the research project.

## **VI. Compensation**

For your participation in this study we will offer you a food voucher for the participation in this study. The food voucher will be generic, so no one will learn of your HIV status and/or membership of an at-risk population when you redeem it.

- You will receive a redeemable food voucher valued at €10 for completing the interview.
- If for any time you wish to cease the interview, your choice will be respected and you will still receive the €10 food voucher

## **VII. Study Results**

The results of this study will be reported in graduate thesis and may also be published in journal articles and books by either myself or by the Estonian Network of People Living with HIV.

If you are interested in receiving study results, please contact myself Tyler Wood at [twood@unbc.ca](mailto:twood@unbc.ca), or contact the Estonian Network of People Living with HIV at [ehpv@ephv.ee](mailto:ehpv@ephv.ee).

## **VIII. Contact For Information about the Study**

If you have any questions about what we are asking of you, please contact the study leader or the research assistant. Their names and telephone numbers are listed at the top of the first page of this form.

## IX. Contact for Complaints

Both the Tallinn Medical Research Ethics Committee of the National Institute UNBC Research Ethics Board have reviewed this study. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, please contact the UNBC Office of Research at 001 250 960 6735, or by email at [reb@unbc.ca](mailto:reb@unbc.ca). Or you can contact the Tallinn Medical Research Ethics Committee at +372 659 3924 or by email at [eetikakomitee@tai.ee](mailto:eetikakomitee@tai.ee). You can also submit your complaint by mail to:

Research Ethics Board  
Office of Research  
Room ADM 2018  
University of Northern  
British Columbia  
3333 University Way  
Prince George, BC, Canada  
V2N 4Z9

Tallinn Medical Research Ethics Committee  
National Institute for Health Development  
Hiiu 42  
Tallinn 11619  
Estonia

## X. Participant Consent and Signature

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on you.

---

Participant Signature

---

Date

---

Printed Name of the Participant signing above

---

Signature of Principle Researcher

---

Date

## Appendix IV

### Project Description and Informed Consent: Unstructured Interviews

#### I. Study Team

##### **Student Researcher/Principal Investigator:**

Tyler Wood, Graduate Student, Interdisciplinary Department (Anthropology/Health and Human Science) University of Northern British Columbia (UNBC), Canada

Phone Number:

Email Address: [twood@unbc.ca](mailto:twood@unbc.ca)

##### **Research Assistant**

*Name*

Phone Number:

Email Address:

##### **Research Assistant**

*Name*

Phone Number:

Email Address:

#### II. Sponsor

This study funded through research awards provided by the University of Northern British Columbia (UNBC). As this study is funded through internal grants of the UNBC, there are no potential conflicts of interest between the researcher and UNBC.

This study is being conducted in partnership with the Estonian Network of People Living with HIV (EHPV), and the EHPV are the main beneficiaries of this research project. The Estonian Network of People Living with HIV is a non-government, non-profit organization that seeks to better the lives of people living with HIV/AIDS and members of at-risk populations in Estonia and works reduce the number of new HIV infections in the country. If you would like to learn more about the EHPV and the services they provide please ask a member of the research team to provide you with brochure or you can visit their website at [ehpv.ee](http://ehpv.ee).

#### III. Purpose of Study

This study, Perspectives of the Influence of Stigma on Access to Antiretroviral Therapy among Russian-speakers living with HIV/AIDS in Ida-Virumaa, is part of a graduate thesis being undertaken by Tyler Wood at UNBC. This study has two objectives:

- 1) To identify and document HIV stigma held by Russian-speakers in Ida-Virumaa, Estonia.

- 2) To explore how HIV stigma influences care-seeking behaviour and access to antiretroviral therapy.

We are inviting people like you, who are Russian-speakers in Ida-Virumaa to help us understand your experience with HIV stigma and how it influences or impacts your life. Participation in this study is entirely voluntary, and you are free to withdraw from this study at any time. You are also free not to answer any questions that make you feel uncomfortable. If you choose to withdraw from this study, any information you provided up to this point will also be withdrawn from the study and securely destroyed.

If you agree to participate in this study, we will:

1. Give you a short form with some questions to complete.
2. You will then participate in a sixty to ninety minute interview with the researcher and a research assistant.
3. The interview will be audio recorded and transcribed at a later date.

#### **IV. Potential Risks of the Study**

We do not think there is anything in this study that could physically harm you. However, some of the questions we ask may seem sensitive or personal, and might upset you. You do not have to answer any questions if you do not want to.

Although we will understand the importance of protecting your anonymity and will do everything possible to secure both your identity and the information you provide, there is the potential risk that information about you that could harm you could be divulged. This divulgence of information might result in serious consequences for you socially (friends, family, relationships) and professionally (work).

At any point in the study, if you reveal that there has been an incident that involves a crime or the physical abuse and/or the neglect of the child (or that there is a risk of such occurring) please be advised that the research must, by according to Estonian law, report this information to the appropriate authorities. There is also a remote possibility that the Estonian Police may officially request or seize a copy of the data or the transcripts. If this does occur, the research team is required, by law, to handover the interview recordings and transcripts to the police.

If at any point in the study, you feel uncomfortable or upset and wish to end your participation, please inform the researcher or research assistant immediately and your wishes will be respected.

Do you understand the potential risks of this study?

☐ Yes

☐ No

---

Signature

---

Date

## **V. Potential Benefit of the Study**

One of the potential benefits of this study is that you will be able to share your perspectives and experiences with someone who will listen to all you have to say and not judge or belittle you in anyway.

The experiences and perspectives you share with this study may have a positive influence on the change of both public perspectives and understandings of HIV and help other living with HIV overcome fear and access antiretroviral therapy.

Others may also benefit from what we learn in this study as the findings could result increasing the accessibility and efficiency of programs, including antiretroviral therapy, designed to increase the quality of life for people living with HIV in Ida-Virumaa.

## **VI. Anonymity and Confidentiality**

Your anonymity will be respected. Information that discloses your identity will not be released without your consent. All electronic and physical documents related to you will be kept in secure location for the duration of the study. You and other participants will not be directly identified in the research records, or in any reports or publication of the completed study. In place of your name, you will be assigned a pseudonym either of your or the researcher's choosing. If you are worried that your position in a specific community would disclose your identity, inform us and we will not disclose the community where you are from. All data and information collected during this study will be stored in a secure location for 4 years. Digital copies of the data will be kept on a secured, password protected external hard drive, and any paper records will be securely stored in a locked office until they are digitally recorded, and then they will be destroyed. After 4 years, the information will then be securely destroyed through the shredding of paper and the deletion of digital files.

Access to the raw data of this study will be highly controlled. Those who will have access include Dr. Michel Bouchard of the UNBC, and Dr. Josée Lavoie of the University of Manitoba. A research assistant, a transcriber and a translator will also be hired to aid in the study, and will be required to sign a confidentiality agreement prior to accessing any hard data.

All efforts will be undertaken to protect your confidentiality and anonymity. However, due to the small study size and that a person you know may have referred you to us your total anonymity cannot be guaranteed.

## **VI. Study Results**

The results of this study will be reported in graduate thesis and may also be published in journal articles and books.

If you are interested in receiving study results, please contact Tyler Wood at [twood@unbc.ca](mailto:twood@unbc.ca) or contact the Estonian Network of People Living with HIV at [ehpv@ephv.ee](mailto:ehpv@ephv.ee).

## **VII. Contact For Information about the Study**

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## **VIII. Contact for Complaints**

Both the Tallinn Medical Research Ethics Committee of the National Institute has approved this study for Health Development and by the UNBC Research Ethics Board. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, please contact the UNBC Office of Research at 001 250 960 6735, or by email at [reb@unbc.ca](mailto:reb@unbc.ca). Or you can contact the Tallinn Medical Research Ethics Committee at +372 659 3924 or by email at [etitikakomitee@tai.ee](mailto:etitikakomitee@tai.ee). You can also submit your complaint by mail to:

Research Ethics Board  
Office of Research  
Room ADM 2018  
University of Northern  
British Columbia  
3333 University Way  
Prince George, BC, Canada  
V2N 4Z9

Tallinn Medical Research Ethics Committee  
National Institute for Health Development  
Hiiu 42  
Tallinn 11619  
Estonia

## **IX. Participant Consent and Signature**

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on you.

---

Participant Signature

---

Date

---

Printed Name of the Participant signing above

---

Signature of Principle Researcher

---

Date

## Appendix V

### Confidentiality Agreement

This study, Perspectives of the Influence of Stigma on Access to Antiretroviral Therapy among Russian-speakers living with HIV/AIDS, is being undertaken by Tyler Wood at the University of Northern British Columbia (UNBC), Canada. This study has two objectives:

1. To identify and document HIV stigma held by Russian-speakers in Ida-Virumaa, Estonia.
2. To explore how HIV stigma influences care-seeking behaviour and access to antiretroviral therapy.

Data from this study will be used the completion of a graduate thesis and possible sequential academic journal articles.

All research assistance working with the principal investigator (Tyler Wood) are expected to conform to the highest ethical standards and up hold the following principles:

- 1): To maintain the safety and security (physical, and social) of all participants, potential participants and partners in this research
- 2) Not share any information regarding participants or potential participants, and partners in any venue, including but not limited to: social media, conversation, and written discourse.

I, \_\_\_\_\_, agree as follows:

1. To keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g. disks, tapes, transcripts) with anyone other than the Principal Investigator (Tyler Wood);
2. To keep all research information in any form or format secure while it is in my possession;
3. Any breach of the confidentiality and anonymity of a research participant(s) will result in my immediate termination.
4. I will not use the Confidential Information for any purpose other than arranging interviews, following up with participants, and the transcribing and or translating of interviews. I will return or destroy all copies of the Confidential Information no later than **June 1<sup>st</sup> 2016**.
5. To return all research information in any form or format to the Principal Investigator when I have completed the research tasks;
6. After consulting with the Principal Investigator, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Principal Investigator(s) (e.g. information stored on computer hard drive).



This study has been approved by both the Tallinn Medical Research Ethics Committee of the National Institute for Health Development and by the UNBC Research Ethics Board. If you have any concerns or complaints about this study, please contact one or more of the following agencies to express your concern:

Research Ethics Board  
Office of Research  
Room ADM 2018  
University of Northern  
British Columbia  
3333 University Way  
Prince George, BC, Canada  
V2N 4Z9  
Phone: 001 250 960 6735  
Email: [reb@unbc.ca](mailto:reb@unbc.ca)

Tallinn Medical Research Ethics Committee  
National Institute for Health Development  
Hiiu 42  
Tallinn 11619  
Estonia  
Phone: +372 659 3924  
Email: [etikakomitee@tai.ee](mailto:etikakomitee@tai.ee)

---

(Print name)

---

(Signature)

---

(Date)

Principal Investigator:

---

(Print name)

---

(Signature)

---

(Date)

## **Appendix VI**

Appendix VI is the informed consent agreement between PLWHIV and *infectionists* that needs to be signed when an individual is first prescribed ART. An English translation of this document is first presented, followed by the original Estonian and Russian versions of the document.

**Patient's informed consent form** \_\_\_\_\_ **20** \_\_\_\_\_

The goal of antiviral drugs is to stop reproduction of HIV in human's body. Antiretroviral therapy (ART) slows down the virus reproduction, prevents healthy cells contamination and significantly reduces the risk of HIV transmission to other individuals. The reduction of viral pressure (the amount of virus on a blood) leads to less damaged immune system, and as a result lowers the risk of getting sick with life-threatening disease due to the low immune system.

HIV treatment should be combined; it means that few ART drugs of different class can be used. Nowadays these drugs should be taken on daily basis. Combined therapy is much more effective and doesn't give virus a chance to become treatment resistant.

To assess treatment efficiency, patient has to make blood tests at least once every 6 months (to determine immune status and viral pressure).

Treatment adherence means that patient strictly follows the schedule and takes prescribed amount while taking drugs (treatment regimen). Treatment regimen is individual for every patient. If patient can't follow treatment regimen because of side effects or any other reason, he or she should inform doctor immediately.

No drug should not be not taken either by accident or wittingly; patient can't change the treatment regimen. If needed the treatment regimen will be changed by a doctor. ART is organized by the government and provided on a base of Nation Health Development Program 2009-2020. To get drugs that were purchased by the government, patient has to sign this document.

I, (patient) \_\_\_\_\_, personal code \_\_\_\_\_

1. understand that I need ART and HIV treatment
2. confirm that I was informed about my health condition, treatment options, meaning and necessity of prescribed treatment, possible danger and consequences that can influence my lifestyle
3. confirm that I will take drugs from a treatment regimen consistently and carefully
4. agree to come personally once a month to the clinic to get drugs; in exceptional cases (long absence from Estonia, immobility) a written covenant with different arrangements can be done.
5. I know that drugs will be free for me as long as I follow the treatment regimen and schedule; a doctor or a panel when necessary assesses abundance of treatment regimen. Repeated violation of treatment regimen gives a panel right to stop a free access to the treatment. In this case patient has a right to continue treatment, but he or she has to get prescription and buy drugs from the pharmacy.
6. I have informed doctor about all the health conditions I am aware of  
Yes \_\_\_\_\_ No \_\_\_\_\_
7. Patient's remarks

8. I know that after I give my consent to start treatment, I can stop treatment at any time; the annulation of consent will be provided in a written form and given to the clinic.

Yes \_\_\_\_\_ No \_\_\_\_\_

9. I have read this consent form and don't want to take ART

Yes \_\_\_\_\_ No \_\_\_\_\_

Patient \_\_\_\_\_  
Signature \_\_\_\_\_

Doctor \_\_\_\_\_  
Signature \_\_\_\_\_

## PATSIENDI TEAVITAMINE JA NÕUSOLEK

\_\_\_\_\_ 20\_\_\_\_, a.

Viirusevastaste ravimite kasutamise ehk antiretroviirusravi (ARV-ravi) eesmärk on takistada inimese immuunsüsteemi kahjustava HI-viiruse (HIV) paljunemist organismis. **ARV-ravi takistab HIV paljunemist ja tervete rakkude nakatumist ning vähendab oluliselt HIV ülekande ohtu teistele inimestele.** Madalam viiruse hulk nakatunud inimese organismis tähendab väiksemat immuunsüsteemi kahjustust, seega ka väiksemat ohtu haigestuda immuunsüsteemi puudulikkusest tingitud eluohtlikku haigusesse.

ARV-ravi peab olema mitmest ravimist koosnev ehk kombineeritud. **Kombineeritud ravi järjepidev (igapäevane) tarvitamine on kõige tõhusam ja hoiab ära viiruse ravim tundetuks muutumise.** Ravi tulemuslikkuse hindamiseks on vajalik viiruse hulga ja immuunsüsteemi kontrollanalüüs vähemalt üks kord iga 6 kuu järel.

Järjepidev ravi tähendab ka seda, et kui arstiga on kokku lepitud, milliseid ravimeid kasutama hakatakse (raviskeem), **tuleb ravimeid võtta täpselt ettekirjutuse järgi.** Kui raviskeemi ei saa järgida kas kõrvaltoimete tõttu või mõnel muul põhjusel, tuleb sellest probleemist oma arstile kohe teada anda. **Ükski ravim ei tohi jääda võtmata ei kogemata ega teadlikult, samuti ei tohi patsient ise raviskeemi muuta.** Vajadusel muudab raviskeemi nakkushaiguste arst.

ARV-ravi on riiklikult korraldatud ja toimub Rahvastiku tervise arengukava 2009-2020 alusel. Riigi poolt ostetud ravimite saamiseks on vajalik käesoleva dokumendi allkirjastamine.

Mina (patsient) \_\_\_\_\_, isikukood \_\_\_\_\_

- ☐ mõistan, et minule on ARV-ravi vajalik;
- ☐ kinnitan, et mind on mulle arusaadaval moel teavitatud minu tervises seisundist, ravivõimalustest, minule määratud ravi olemusest ja otstarbekusest ning sellega kaasneda võivatest kõrvaltoimetest ja võimalikest tagajärgedest, mis võivad mõjutada minu edaspidist elukorraldust;
- ☐ kinnitan, et tarvitan raviskeemis kokku lepitud ravimeid järjepidevalt ja korralikult;
- ☐ nõustun ravimite raviskeemis üks kord kuus isiklikult järel käima; erandjuhtudel (nt pikaajaline Eestist eemal viibimine, liikumisraskused) ja erandjuhtu kirjeldaval kirjalikul kokkuleppel raviskeemiga võin kokku leppida teistsuguse ravimite kättesaamise viisi;
- ☐ olen teadlik, et ravi jaoks vajalikud ravimid on minu jaoks tasuta seni, kuni järgin raviskeemi nõuetekohaselt; raviskeemist kinnipidamist hindab arst ja vajadusel ravikonsiilium, kellel on õigus korduvate raviskeemi rikkumiste korral tasuta ravimite andmine lõpetada; sellisel juhul saab ravi jätkata ravimeid retsepti alusel ja tasu eest apteegist ostes.

JAH EI

- Olen teavitanud arsti kõigist minule teada olevatest minu tervisega seotud asjaoludest. ☐ ☐

7. Patsiendi märkused, erisooovid: \_\_\_\_\_

- Olen teadlik, et võin nõusoleku raviks pärast nõusoleku andmist igal ajal tagasi võtta; nõusoleku tagasivõtmise vormistan kirjalikult ja edastan selle teadmiseks raviskeemile. ☐ ☐

- Olen tutvunud patsiendi teavitamise ja nõusoleku vormi sisuga, kuid keeldun antiretroviirusravist. ☐ ☐

Patsient \_\_\_\_\_  
nimi

Arst \_\_\_\_\_  
nimi

Allkiri: \_\_\_\_\_

Allkiri: \_\_\_\_\_

## Информированное согласие пациента

20 \_\_\_\_ . а.

Цель использования противовирусных лекарственных препаратов - остановить воспроизведение вируса иммунодефицита человека в организме. Антиретровирусная терапия (АРТ) замедляет размножение вируса, препятствует инфицированию здоровых клеток и существенно уменьшает риск передачи ВИЧ-инфекции другим людям. Снижение вирусной нагрузки (количество вируса в крови) означает меньшее повреждение иммунной системы и, соответственно, меньший риск заболеть опасным для жизни заболеванием из-за сниженного иммунитета.

Лечение ВИЧ-инфекции является комбинированным, т.е. одновременно применяются сразу несколько АРТ препаратов разных классов. В настоящее время эти препараты необходимо принимать ежедневно. Комбинированная терапия гораздо эффективнее и не дает вирусу возможности выработать устойчивость к лечению (резистентность).

Для оценки эффективности лечения необходимо делать анализы крови, по меньшей мере, один раз в 6 месяцев (определение иммунного статуса, определение вирусной нагрузки).

Приверженность к лечению означает прием лекарственных препаратов с **точным соблюдением графика приема и дозировки** (схемы лечения). Схема лечения подбирается индивидуально. Если схему лечения невозможно соблюдать из-за побочных явлений или по какой-либо другой причине, то следует немедленно сообщить об этом своему лечащему врачу.

**Ни один лекарственный препарат не должен остаться не принятым ни случайно, ни сознательно, пациент не должен сам изменять схему лечения.** При необходимости схему лечения изменит врач-инфекционист. АРТ организована государством и осуществляется на основании Программы развития здоровья народонаселения на 2009-2020 годы. Для получения закупленных государством лекарственных средств необходимо подписать настоящий документ.

Я, (пациент) \_\_\_\_\_, личный код \_\_\_\_\_

1. ☐ понимаю, что мне необходима антиретровирусная терапия, то есть лечение ВИЧ- инфекции (в дальнейшем лечение)
2. ☐ подтверждаю, что меня, понятным мне образом, проинформировали о моем состоянии здоровья, о возможностях лечения, о сущности и целесообразности назначенного мне лечения и о возможных сопутствующих этому опасностях и возможных последствиях, которые могут повлиять на дальнейшую организацию моей жизни
3. ☐ подтверждаю, что буду принимать лекарственные препараты, оговоренные в схеме лечения, последовательно и аккуратно
4. ☐ согласен (согласна) один раз в месяц лично приходить в лечебное учреждение за лекарственными препаратами; в исключительных случаях (например, длительное отсутствие в Эстонии, проблемы с самостоятельным передвижением) и по письменной договоренности с лечебным учреждением могу договориться о другом способе получения лекарственных препаратов
5. ☐ я знаю, что необходимые для лечения лекарственные препараты, будут для меня **бесплатными** до тех пор, пока я соблюдаю схему и режим лечения в соответствии с требованиями; соблюдение режима лечения оценивает лечащий врач, при необходимости врачебный консилиум; при повторных нарушениях режима лечения у врачебного консилиума есть право прекратить бесплатное лечение. В этом случае пациент может продолжить лечение за свой счет, выкупая соответствующие препараты в аптеке по рецепту.
6. Я сообщил (-а) врачу обо всех известных мне обстоятельствах, связанных с моим здоровьем

да нет  
☐ ☐

7. Примечания пациента, особые пожелания:

8. Я знаю, что после того, как дам согласие на лечение, могу в любое время отказаться от согласия на лечение; отзыв согласия будет оформлен в письменном виде и с целью информирования передан лечебному учреждению.

☐ ☐  
☐ ☐

9. Ознакомлен с вышеуказанным. Отказываюсь от антиретровирусной терапии

Пациент \_\_\_\_\_  
Имя

Врач \_\_\_\_\_  
Имя

Подпись \_\_\_\_\_

Подпись \_\_\_\_\_

